

72-102

HOSPITALS IN CRISIS: FINANCIAL IMPACT OF AIDS ON NEW YORK CITY'S HOSPITALS

HEARING

BEFORE THE

TASK FORCE ON URGENT FISCAL ISSUES

OF THE

COMMITTEE ON THE BUDGET

HOUSE OF REPRESENTATIVES

ONE HUNDRED FIRST CONGRESS

SECOND SESSION

APRIL 6, 1990
NEW YORK CITY

Printed for the use of the Committee on the Budget

Serial No. 4-5



U.S. GOVERNMENT PRINTING OFFICE

29-687

WASHINGTON : 1990

For sale by the Superintendent of Documents, Congressional Sales Office
U.S. Government Printing Office, Washington, DC 20402

COMMITTEE ON THE BUDGET

LEON E. PANETTA, California, *Chairman*

RICHARD A. GEPHARDT, Missouri
MARTY RUSSO, Illinois
ED JENKINS, Georgia
MARVIN LEATH, Texas
CHARLES E. SCHUMER, New York
BARBARA BOXER, California
JIM SLATTERY, Kansas
JAMES L. OBERSTAR, Minnesota
FRANK J. GUARINI, New Jersey
RICHARD J. DURBIN, Illinois
MIKE ESPY, Mississippi
DALE E. KILDEE, Michigan
ANTHONY C. BEILENSON, California
JERRY HUCKABY, Louisiana
MARTIN SABO, Minnesota
BERNARD J. DWYER, New Jersey
HOWARD L. BERMAN, California
ROBERT E. WISE, Jr., West Virginia
MARCY KAPTUR, Ohio
JOHN BRYANT, Texas

BILL FRENZEL, Minnesota
Ranking Republican Member
WILLIS D. GRADISON, Jr., Ohio
WILLIAM F. GOODLING, Pennsylvania
DENNY SMITH, Oregon
WILLIAM M. THOMAS, California
HAROLD ROGERS, Kentucky
RICHARD E. ARMEY, Texas
JACK BUECHNER, Missouri
AMO HOUGHTON, New York
JIM McCRERY, Louisiana
JOHN R. KASICH, Ohio
DEAN A. GALLO, New Jersey
BILL SCHUETTE, Michigan
HELEN DELICH BENTLEY, Maryland

TASK FORCE ON URGENT FISCAL ISSUES

CHARLES E. SCHUMER, New York, *Chairman*

*LEON E. PANETTA, California
*RICHARD A. GEPHARDT, Missouri
BARBARA BOXER, California
JIM SLATTERY, Kansas
JOHN BRYANT, Texas

*BILL FRENZEL, Minnesota
WILLIS D. GRADISON, Jr., Ohio
RICHARD K. ARMEY, Texas
WILLIAM M. THOMAS, California
JIM McCRERY, Louisiana
BILL SCHUETTE, Michigan

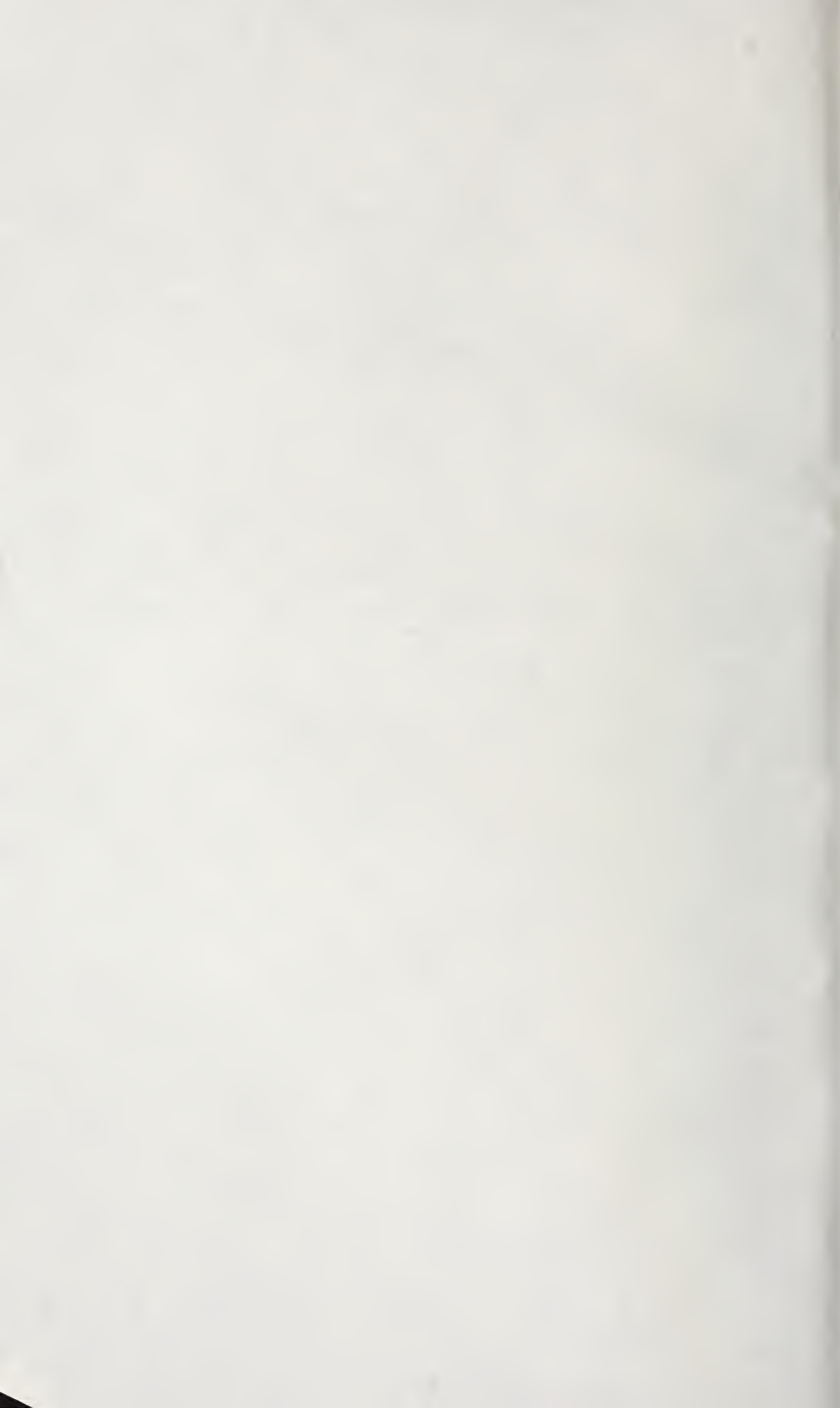
LYNNE RICHARDSON, *Associate and Task Force Coordinator*

(II)

*Ex Officio.

CONTENTS

| | Page |
|---|--------|
| Statement of: | |
| Campbell, Gloria Bailey, Nurses' Aide for AID'S Patients, Bellevue Hospital | 28 |
| Channing, Alan H., Executive Director, Bellevue Hospital | 9 |
| Doe, Jane, Person Living With AIDS | 28 |
| Fraser-Howze, Debra, Executive Director, Black Leadership Commission on AIDS | 39 |
| King, Debby, Executive Vice President, Drug, Hospital and Health Care Employees Union, Local 1199 | 32 |
| McCoury, Steven, Person Living With AIDS | 23 |
| Meyers, Dr. Woodrow A., Jr., Commissioner, New York City Department of Health | 6 |
| Peterson, Robert,, Policy Associate, Gay Men's Health Crisis | 34 |
| Raske, Kenneth E., President, Greater New York Hospital Association | 14 |
| Saltzman, Dr. Brian, Beth Israel Hospital | 29 |
| Santorio, Robert, Person Living With AIDS | 26 |
| Scheuer, Hon. James H., a Representative in Congress from the State of New York | 3 |
| Schrier, Kathy, Director of Education, American Federation of State, County and Municipal Employees, District Council 37 | 37 |
| Smith, Ron, Person Living With AIDS | 25 |
| Prepared statement submitted for the record by: | |
| Channing, Alan H. | 69 |
| Myers, Woodrow A., Jr., M.D. | 80 |
| Peterson, Robert | 43 |
| Raske, Kenneth E., with attachment from NEWSCAST, June-July 1989 entitled: The Shaping of an AIDS Payment Policy in New York State | 56, 66 |
| Schrier, Katherine | 49 |



HOSPITALS IN CRISIS: FINANCIAL IMPACT OF AIDS ON NEW YORK CITY'S HOSPITALS

FRIDAY, APRIL 6, 1990

HOUSE OF REPRESENTATIVES,
TASK FORCE ON URGENT FISCAL ISSUES,
COMMITTEE ON THE BUDGET,
York York, NY.

The Task Force met, pursuant to notice, at 11 a.m. in York York, NY, Hon. Charles E. Schumer, Chairman of the Task Force, presiding.

Mr. SCHUMER. The hearing will come to order. I am Congressman Charles Schumer, and am the Chairman of the Task Force on Urgent Fiscal Issues of the House Budget Committee, which has convened this hearing. I want to thank all of the Budget Committee staff and everyone else who came up from Washington to be here.

I have a brief opening statement and then we will begin the panel.

Let me begin by noting that when it comes to health care, America is somewhat hypocritical. Our health care ideal is that all Americans should have equal access to adequate care, yet our actions have not been in line with this ideal. The fact that we don't provide enough money to do the job is evident from one end of this metropolitan area to the other. Thus, faced with declining Governmental assistance, yet expected to be the caregiver of last resort for society's most daunting problems—AIDS, drug abuse, homelessness—hospitals have become one giant shock absorber, buffeted from all sides. Hospitals are supposed to address the ideal that everyone gets the best health care and the reality is that there isn't enough money and they are bounced between those two ideals.

As a result, York York City's hospitals are facing a crisis of unprecedented proportion in their history and unparalleled anywhere else in the country. The most visible symptom of the city's ailing health care system—hospitals so overcrowded that none of the city's sick, rich or poor can count on being treated—is but an indication of a more fundamental social and administrative crisis. Any one of these problems alone—declining revenues, rising care demands, aging facilities—might have been viewed as a full scale crisis in the past. Converging all at once, however, they have put an almost unimaginable strain on the city's hospitals.

Yes, the hospitals are doing an excellent job under the circumstances, but even Marcus Welby would lose his cool with these pressures.

Today's hearing will explore New York's hospital crisis in general, while focusing specifically on one of the biggest problems facing New York's hospitals today—caring for people living with AIDS.

York York is the undisputed epicenter of the country's epidemic of AIDS. At least 25 percent of the Nation's AIDS patients live in New York, and AIDS is now the leading cause of death in our city among women aged 25 to 34 and among men 25 to 44. All you have to do is scan the obituaries of any newspaper and you will see everyday a young man 35 years old, talented, his whole career ahead of him, now dead. At least 15,000 people have died from AIDS in the city to date, 10,000 more are dying, and up to 250,000 people are infected with the AIDS virus.

The human costs of AIDS are devastating. We have seen those time and time again. We saw them on our tour a few minutes ago. Two young men, both productive once, able to contribute to society, now sitting in a hospital and awfully facing what is in front of them.

The financial costs are also astounding. The city's Office of Management and Budget estimates that over \$1 billion will be spent on AIDS this year in New York City alone, and that the total direct spending will rise to \$2 billion by 1994. New York's Finance Commissioner, Carol O'Cleireacain, recently put these figures in perspective in noting that by 1994, city spending along on AIDS will equal 80 percent of the police department budget, four times the size of the city's fire department budget, and 4 percent of the city's total budget.

The impact of AIDS on New York's hospitals is staggering. Currently, AIDS patients fill almost 10 percent of the city's hospital beds. By 1994, AIDS patients will require an additional 2,300 beds, the equivalent of four new medium sized hospitals in this city. They will also require an additional 1,100 nursing home beds, 2,600 housing units, and 3,000 home care slots, all at a cost of approximately \$7.2 billion, according to a recent forecast by the New York City AIDS Task Force. Currently, the average public hospital in New York loses over \$600,000 each year on AIDS care alone, and the average private hospital loses over \$200,000 per year.

One thing is clear—New York's hospitals cannot meet this crisis alone anymore. They have tried valiantly. They are struggling. The kind of care we saw downstairs is excellent care that every citizen who has AIDS ought to be getting. But, without Federal help, two things will happen. First, thousands of people with AIDS will no longer be admitted to any hospital, and second, many of New York City's hospitals desperately needed beds will close. That is why this year I have proposed a major initiative in the budget. An initiative that would give hospitals that are heavily impacted with AIDS patients extra Federal dollars, extra Medicaid dollars, so that they can begin to live with this crisis. I am optimistic that this initiative will be placed in the budget and, of course, after we get the money in the budget, the program has to be crafted. That is where Henry Waxman, the Chairman of the Health Subcommittee, and Jim Scheuer, a Member of that subcommittee, come into play. I have talked with Chairman Waxman and he has guaranteed me that if the money is placed in the budget, the hospital initiative that I

have been fighting for and worked on with so many people in this room, will be put into place as a program.

What I propose in the budget is additional coverage to hospitals that care for a large number of AIDS patients. The initiative establishes a new payment for each AIDS Medicaid patient in an amount of no less than 25 percent of the current per patient Medicaid reimbursement. We have talked to the people at the State and we think we can change the formula so that New York State will not be as overburdened as it might be. I am optimistic for chances of passage of this initiative.

The hearing today should help tremendously. We have to let our colleagues know of the huge problem people with AIDS face here in New York and in cities in the country. We have to let our colleagues know of the huge burden our hospitals face, given that they have been asked to be the shock absorbers of the health care system. And, I am confident that when this record is made available to my colleagues on the Budget Committee who are not from New York, but who are from places like Kansas, Texas, and North Dakota, they will see the real need for our problem and that the initiative will pass. That is why being here today is so important, and I want to thank everybody for coming. We invited all the Members of the New York City delegation. Many are away because we are on holiday break, but Jim Scheuer is here and I want to thank him for coming and ask him to say a few brief words.

STATEMENT OF HON. JAMES H. SCHEUER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK

Mr. SCHEUER. Thank you very much Mr. Schumer, I want to congratulate for your leadership in arranging this hearing. It is a very important hearing and I am happy to participate.

As the senior Member of the House Subcommittee on Health, I have introduced a piece of legislation with Henry Waxman direly aimed at improving the status of New York City's hospitals in terms of this overwhelming burden that has fallen upon their shoulders, namely the burden of treating AIDS patients and it is that legislation, the Waxman-Scheuer or the Scheuer-Waxman legislation as I prefer it to be known, that Chuck Schumer is talking about finding, in a short place, in the final budget that emerges. Of course, as a member of the delegation and as dean of the New York City delegation, I am intimately aware as Mr. Schumer is, of course, of the crisis we are facing today in New York City.

AIDS and other illnesses linked with the human immuno-deficiency virus which is known as HIV, of course, have become a crisis for our entire Nation's health care system, but no where more acutely than in our own city, in New York City, and the crisis is worsening. Many of those in high risk groups without health care, without health insurance, either have it or lose it during the illness. Officials with the Centers for Disease Control in Atlanta, part of the National Institutes of Health, say that more infants will be infected with AIDS this year than any time in the history of the epidemic. There is a growing population of abandoned HIV-infected children that is placing an enormous burden on the city's not only the health service but the entire social fabric

of the city's services. Boarder babies, as they are known, can cost the system up to \$90,000 or \$100,000 a year. New York City alone is projected to have 60,000 AIDS cases by 1993—60,000 AIDS cases.

Drug users are expected to make up 90 percent of the total, meaning that we cannot separate the AIDS crisis from the drug crisis, the intravenous drug use crisis that seems to be expanding expedientially and out of control. We are grossly underfunding drug services, education, treatment, rehabilitation, and we are grossly underfunding AIDS treatment, rehabilitation and control, so we are underfunding both the means of controlling drug use and treatment of AIDS itself, and we are not facing honestly the imperative that is facing society of cutting off the expansion of AIDS and that must mean that society has to face up to the question of mandatory reporting of AIDS on a totally confidential basis, so that society can seek out the sex partners and the drug partners of those afflicted with AIDS and try and warn them of the death threat that they are facing if they continue their present practice without a basic change in behavior. We must bite the bullet and find a way of protecting confidentiality. But, also, protecting the sex and the drug partners of AIDS patients so that they too will not catch the disease. We must cut off that chain.

Now, AIDS is very much concentrated in New York and even here it is very much concentrated in a few hospitals like this wonderful institution that we are in now, Mother Cabrini. AIDS, of course, has been diagnosed in every State of the country, but most AIDS cases are concentrated in New York, California, New Jersey, and Texas where all of those hospital systems are overwhelmed, as is our system in New York City.

It is interesting to note that 20 percent of all of our Nation's hospitals, just 20 percent, treat 80 percent of the AIDS patients and only 5 percent of our Nation's hospitals treat over 50 percent of our AIDS patients and I see Dr. Myers nodding with a sort of a sad smile on his face—yes, that is the problem that Dr. Myers has to face that a very small percentage of the Nation's hospitals concentrated in New York treat perhaps 50 percent of all of the AIDS patients in the country and, of course, New York City has been hit harder than any other city in the country by the AIDS epidemic and the city and the State of New York should be commended for their efforts and I want to congratulate you Dr. Myers for the marvelous leadership that you are showing in facing up to AIDS.

New York City has more reported cases of AIDS than any other State and we have allocated more resources per capita than any other State in the country with the possible exception of Hawaii and the District of Columbia. Nevertheless, no matter how herculean your efforts Dr. Myers and those of your colleagues, Ken Raske, and others, New York can't go it alone. The Federal Government must come in and must engage also in the fight before the health care systems of New York and other similarly effected states just collapse under the burden.

Now, to initiate a truly comprehensive Federal approach to the AIDS crisis, I have introduced along with Congressman Henry Waxman, H.R. 4080, the Medicaid AIDS and HIV Amendments of 1990 and it is this legislation that Congressman Schumer is striv-

ing valiantly to make sure is included in our budget, so the Scheuer-Schumer team is really making tracks in producing—

Mr. SCHUMER. Am I allowed to say Schumer-Scheuer?

Mr. SCHEUER. In Brooklyn, I might add, it is always known as the Schumer-Scheuer team.

Mr. SCHUMER. At least in the 10th District.

Mr. SCHEUER. What this bill would do would be to reduce the burden on New York City's health care system by making AIDS treatment available for Medicaid reimbursement. The bill I have introduced with Congressman Waxman that Congressman Schumer is supporting will increase Medicaid assistance to New York by about 25 percent enabling the city to spend its very scarce health care funds on other very vitally needed services, like prenatal, postnatal, immunizations, family planning, and other urgently needed preventive health services.

Now, we have all heard from childhood that an ounce of prevention is worth a pound of cure. In this case, it is worth a ton of cure. Thousands or small millions of dollars today will save us billions of dollars in the future, literally billions of dollars. The cost benefit calculus of spending money on AIDS today both in treatment, education and in stopping the dissemination, the further spread of the disease, has a return on capital investment that is almost astronomical. We can't fail to make that investment and with Chuck Schumer's help, we will make it.

Mr. Chairman, I am looking forward to the testimony today and I know they will outline the answer to the truly awesome challenge faced by this Nation and especially by this city. Thank you.

Mr. SCHUMER. Well, thank you very much for coming and for your leadership on this issue.

I apologize to our witnesses. I know they have waited a long time. The tour took a little longer than we had thought but I think it was well worth it in terms of seeing the problem first hand. Before I begin, I also want to thank Cabrini Hospital. They have been wonderful in helping us plan today's hearing. As you know, their reputation in terms of treating people with AIDS is superb and we have seen first hand evidence of that today. Their work has been exemplary, so, I want to thank the people who took us on the tour and the administrators and everyone else at Cabrini.

Now, let's get to our first panel. We have some of New York's finest health care leaders on this panel and they will describe for us the crisis facing New York's hospitals, focusing particularly on the impact of AIDS on our health care system.

We will have all three panelists testify and then we will ask questions. Our first panelist is a man who needs no introduction for the great job he has done in the short time he has been here in New York City, Dr. Woody Myers. He is the city's brand new Health Department Commissioner. This is his second public appearance and let's hope you have many more auspicious ones, Dr. Myers. I really look forward to the testimony and want to welcome you to the hearing and to your new position.

Dr. MYERS. Thank you very much.

Mr. SCHUMER. I don't know if you did this in Indiana, but we read the entire statement into the record so if you wish to add, delete, omit, ad lib, just go right ahead. Your time is our time so

feel free, but, without objection, your entire statement will be read into the record.

**STATEMENT OF DR. WOODROW A. MYERS, JR., COMMISSIONER,
NEW YORK CITY DEPARTMENT OF HEALTH**

Dr. MYERS. Thank you very much Mr. Chairman and thank you very much Mr. Scheuer.

I must say that I have indeed testified before Congressional panels before and testified before many legislative panels, but I have yet to find as an enlightened a delegation as the one before me. I would hope that other delegations in other States would have had that kind of enlightenment. I think we would have been much further along down the pike then we are today.

The impact on HIV on York York City is significant as you have already noted. Nowhere else in the Nation are the challenges of the new epidemic of AIDS making themselves felt as strongly as here in York York. The cumulative number of AIDS cases here, more than 25,000 as of March 1990, exceeds the combined total from the next four U.S. cities.

More than 15,200 York Yorkers have died from AIDS, now the leading cause of death among York York men aged 30 through 44, women aged 25 through 39, and children aged 1 through 4. Almost 4,000 women and 600 children have been diagnosed with AIDS in York York City.

We estimate that between 125,000 and 235,000 York Yorkers are infected with HIV. This includes up to 60 percent of the city's estimated 200,000 intravenous drug users, 50,000 men who have had sex with men and thousands of others, primarily women, infected through heterosexual contact with an IV drug user. About 1,800 infants are born to HIV-infected mothers in York York City each year; approximately one-third of these children will develop HIV illness by 15 months.

It is now clearly recognized that the burden of the epidemic on our hospitals and in our communities extends far beyond the number of CDC-defined AIDS cases. HIV-infected people suffer many clinical and functional problems prior to being diagnosed with AIDS and this full spectrum of HIV almost requires a wide range of medical and support services. For 3 years, we have worked hard to shift the focus of service delivery planning away from CDC-defined AIDS to the broader more appropriate concept of HIV-illness.

Epidemics of syphilis and tuberculosis parallel the HIV epidemic in York York City and there is now a strong basis for believing that many new cases of tuberculosis are a result of HIV infection. We continue to study whether syphilis and other sexually transmitted diseases facilitate the spread of HIV through genital lesions. Almost 8,000 cases of syphilis and 2,600 cases of tuberculosis were reported in York York City in 1989.

By 1993, we project that 60,000 people will have developed AIDS in New York City, more than double the present number; 48,000 people will have died. More than 10,000 new cases will be diagnosed in 1993 alone, almost double 1989's figure. If we count the addicts who are sick and dying from tuberculosis and other dis-

eases related to HIV infection but not officially classified as AIDS, projections would be very much higher. CDC now reports that the epidemic is leveling off in some respects. We note, however, that even if the rate of growth for new AIDS cases has slowed, we will not see much relief here in the very near future. Every year, New York City will continue to see a very large number of new HIV cases requiring clinical monitoring and care and other services.

Two trends in this epidemic will have great impact during the next 5 years. The first is the epidemic's changing profile, marked by the increasing role of substance abusers. In 1989, IV drug users accounted for 46 percent of new AIDS cases in contrast to the early days of the epidemic where almost three-quarters of the reported cases of AIDS in New York City were among men who have sex with men.

Increasingly, cocaine and crack fuel the spread of HIV infection among drug users and their sex partners. Those who inject cocaine do so more often than heroin users, and are thus at greater risk of infection through shared needles. The intense crack epidemic, with its fierce addiction and sex-for-drugs transactions, is related to increases in heterosexually transmitted HIV infection as well as to explosive recent increases in other sexually transmitted diseases. This occurs in areas of York York where genital ulcer disease is common and there has been a high prevalence of HIV infection. We are conducting a study at a sexually transmitted disease clinic in the South Bronx. Among the crack users there who deny IV drug use, male to male sexual activity or sexual contact with an intravenous drug user, 18 percent have tested positive for the human immuno-deficiency virus.

HIV-related sickness and death in drug users, their sex partners and children are battering the city's poor and minority residents. Blacks and hispanics, disproportionately represented among the poor and therefore among drug users, comprise over 60 percent of AIDS cases reported among all New Yorkers, 84 percent of cases reported among women, and 90 percent of those reported among children.

The second development which will have great impact is the growing demand for clinical preventive and social services as a result of the broadening treatment horizon. More effective therapies are rapidly becoming available for treating and preventing opportunistic infections. The Centers for Disease Control has recommended that all HIV infected persons be medically evaluated every 6 months. Recent studies have shown that the drug AZT slows the progress of HIV illness in asymptomatic people and those with early symptoms, making tens of thousands of York Yorkers candidates for treatment.

The Department of Health estimates that possibly half of all HIV infected New Yorkers already have T4-cell counts below 500. This is an indication that their immune systems are significantly compromised. The estimate is important in light of current treatment standards for early intervention that can prolong life. Our analysis suggests that between 37,000 and 70,000 persons should be assessed for a preventive treatment regimen of low dose AZT and that an additional 25,000 to 47,000 should be receiving other medical treatments to prevent PCP in addition to AZT. The benefit to

the thousands of HIV-infected New Yorkers could be great, but meeting this treatment obligation would add yet another significant new burden to an already stressed treatment system.

Mr. Chairman, I am going to move to the recommendations to Congress section of my testimony because much of what I was planning to say about hospitals in New York City I am sure will be covered by the testimony of the leaders around me. We have several recommendations to make to the U.S. Congress.

In order to relieve the enormous burdens faced by high impact areas in the course of the HIV/AIDS epidemic, Congress should enact the Comprehensive AIDS Resources Emergency Act of 1990. This bill would provide a major infusion of funds to local health delivery systems so that medical treatment, early intervention, prophylactic therapies and support services can be enhanced or expanded.

In order to promote appropriate early intervention, Congress should enact the Medicaid AIDS and HIV Amendments of 1990 which would give States the option to expand Medicaid benefits to a broader portion of our underserved HIV infected communities.

In order to provide critically needed permanent and supported housing as a necessary component of the HIV/AIDS continuum of care, Congress should increase Federal funding for housing. We are particularly concerned Mr. Chairman that the Department of Housing and Urban Development fiscal year 1991 budget does not include specific funds for this purpose. The city supports the AIDS Housing Opportunity Act.

In order to enable persons with HIV related illness to return to or remain in their own homes, Congress should provide the full funding for the home health care services. The New York City AIDS Task Force estimates that by 1993, the need for home care will be more than seven times the current capacity to serve indigent clients.

In order to conduct a major HIV/AIDS prevention initiative among substance using populations, Congress should expand the Alcohol, Drug Abuse and Mental Health Block Grant and AIDS Prevention Programs. A significant Federal increase in the ADAMHA block grant will yield critically needed drug treatment slots.

In order to attract the types of health providers, nurses, social workers, physicians—integral to the provision of a continuum of care for HIV infected and ill persons, Congress should revitalize the National Health Service Corps, and designate high impact, underserved areas.

Mr. Chairman, this is a program with which I had personal experience in my days as a medical student. It was a program that in those days, during the Carter Administration, was used, I think, quite appropriately and targeted to those areas of the country that needed physicians and did not have them. The program's bureaucracy and infrastructure is already in place. Let's not abandon it. Let's use it now that we really need it in places like York York City.

In order to effectively address the particular characteristics of HIV/AIDS as a chronic, often fatal disease with a diminished survival time, Congress should suspend the 24-month waiting period

for Medicare eligibility for people with HIV illness or AIDS. Without hastened eligibility for people with AIDS, many will die before the 24-month waiting period concludes.

And to help ease the burden on the small number of hospitals already referred to by Mr. Scheuer caring for the majority of patients, the Medicaid disproportionate share requirements in our opinion should be expanded. Specifically, States should be required to provide Medicaid rates that fully cover the cost of inpatient and outpatient AIDS/HIV ill care, thus encouraging all hospitals to serve these patients. The Federal Government should also require that state Medicaid plans include provisions for the adequate participation of all hospitals in caring for the HIV-ill or persons with AIDS.

And, finally, in order to further support and encourage at-risk populations to avail themselves to early medical intervention, Congress should enact strong legislation to protect HIV-infected individuals from discrimination, and to assure the anonymity and confidentiality within the testing process.

Mr. Chairman, thank you very much for the opportunity to speak before you today, my fifth day as the Commissioner of Health in the great city of New York. At the appropriate time, I and/or my staff would be happy to answer those questions that you put before us.

[The prepared statement of Dr. Myers may be found at the end of the hearing.]

Mr. SCHUMER. Thank you Dr. Myers for your comprehensive and excellent testimony.

We are next honored to have on our panel Alan Channing. Mr. Channing is the executive director of Bellevue Hospital, a neighboring hospital that, like Cabrini, is struggling and struggling very well I might say with all the burdens that they have right now. He is representing the Health and Hospitals Corp. Bellevue is one of the largest providers of care for people living with AIDS in the country, so Mr. Channing is well placed to talk about this subject. HHC hospitals care for an incredible number of AIDS cases and deserve credit for their herculean efforts.

Mr. Channing, as with Dr. Myers, your entire statement will be read in the record and you may proceed as you desire.

STATEMENT OF ALAN H. CHANNING, EXECUTIVE DIRECTOR, BELLEVUE HOSPITAL

Mr. CHANNING. Thank you Mr. Chairman and Congressman Scheuer. I am Alan Channing, the executive director of Bellevue Hospital, one of the member institutions of the New York City Health and Hospitals Corp., and I appreciate the opportunity to be here today to discuss the impact of AIDS on our hospital and to support your legislative initiative to support hospitals treating the disproportionate share of AIDS patients.

It is clear from both of your comments that you understand the issues very well and the impact on the hospitals in York York City.

Our hospitals continue to operate in an environment of unprecedented overcrowding. We are struggling against staggering odds to meet the needs of the most urgent of the city's patients in a time of

rapidly escalating health care demands. The AIDS epidemic has grown relentlessly through the eighties, along with the epidemics of drug abuse and mental illness. The incidence of poverty, homelessness and violence has also grown dramatically. Now, one New Yorker out of five lacks medical insurance, most of them women and children.

The exploding demand has placed increased pressure on the acute care hospitals in the city and as everybody has already mentioned, the scarcity of primary and preventive care resources have just made this problem increasingly worse. Neither the inpatient or outpatient services or preventive services are financed adequately by the reimbursement system.

We look at the impact of the AIDS issue—it has been especially dramatic at HHC. We care for more people with AIDS than any other single provider in New York City or, for that matter, in the entire country. Our average daily AIDS inpatient census across the HHC system, is now 625—triple what it was in 1985. At Bellevue alone, we have 150 to 155 patients on any given day, more than any other hospital in the country. With only 16 percent of the medical-surgical bed capacity in the city, we provide over one-third of the city's inpatient services for patients with AIDS. We have had what is approaching a decade's worth of unprecedented experience and in the process we have had to grapple with the unique and challenging realities of this epidemic. I would like to just touch on a couple of these.

First, as everyone knows, AIDS care involves a complex interaction of medical, social and psychological needs that demands an interdisciplinary approach and case management services in both inpatient and outpatient settings to ensure continuity of care for our patients. Reimbursement for these services has been historically nonexistent or particularly inadequate. Without the appropriate payment, the already disproportionate burden on the public hospitals as the providers of last resort will increase.

Second, the interrelationship between AIDS and IV drug abuse has brought attention to the larger implications of financing for drug treatment programs throughout the community.

Third, AIDS has helped bring to light the inadequacies of the post-hospital care system. Since the level of care required by AIDS patients often varies significantly over the time of the disease, we need to look at maintaining the continuity of care here that might be appropriate for each individual patient. To do that, the appropriate financial incentives for the development and provision of a wide range of services have to be included. Looking at chronic care services, home care, supportive housing and expanded ambulatory care. In New York City, long stay cases—those with total patient days over 30 days, where a patient stays in the hospital over 30 days—plays a significant important role in hospital use by AIDS patients. It also has an impact on other people having the ability to get into an acute care hospital. If every AIDS patient could be discharged to an appropriate long-term care facility or service after 30 days, we would essentially add 350 acute care beds to the system in New York.

Finally, homelessness is a particularly difficult problem with patients with AIDS. This must again be addressed in a larger context

of housing needs throughout the city. On any given day, half of the 155 patients at Bellevue who are HIV positive are considered to be homeless and undomiciled—a significant burden on the hospital and on the rest of the care system.

HHC has had to deal with each and everyone of these issues. We have 11 acute care hospitals that represent 7,800 beds, 5 long-term care facilities with 2,500 beds, 5 neighborhood family care centers, 12 smaller community primary care centers, and 6 certified home health care agencies. In addition to that, as you know, we operate the Emergency Medical Service System in the city.

Public hospitals like HHC affiliates have traditionally been on the cutting edge of all the social and economic changes in our society. Most recently, we have been at the forefront in confronting the AIDS crisis. Our AIDS patients tend to be sicker and poorer than AIDS patients seen in the other hospitals. Eighty-five percent of our AIDS patients are emergency admissions, that is, they come in the hospital in acute distress and are admitted through the emergency room. A full 75 percent of them contracted the virus as a result of IV drug use, either through direct use, sexual contact with an IV user or born to an IV drug abuser. By contrast, the IV drug abusers make up less than 10 percent of the AIDS population in San Francisco and just over one-third of the AIDS population in the city of New York. One-quarter of our AIDS patients are women; nationally that number is less than 10 percent. Almost 90 percent of our AIDS cases are members of the minority community compared with 40 percent nationally. In terms of payor mix, 80 percent of our patients are Medicaid which is almost twice the percentage of nonagency hospitals.

Projections for the future are grim. Between June 1989 and the end of 1993, cumulative AIDS cases citywide will triple; new cases will double. To handle this growing caseload, we will need over 3,000 more acute care beds citywide which as you pointed out in your opening remarks is the equivalent of between six and seven new hospitals of 500 beds each. Without these new beds, by 1993, 39 percent of HHC's acute care beds, medical and surgical beds, and 17 percent of the total medical surgical beds in the city will be occupied by people with AIDS or HIV illness.

Today at Bellevue, 22 percent of our medical surgical beds have HIV positive patients in them.

Other services will also be needed in addition to acute care. Over the next 5 years, approximately 200,000 patients or people will need outpatient therapy, nearly 1 million visits per year by 1993. With the recent advances in treatment procedures, these services will be critical to the success of our fight against this disease. A full 25 percent of the city's AIDS patients being discharged from the hospital will need some form of housing including supportive residences. Others will need rent assistance to enable them to remain in their own homes. This will mean roughly 1,590 supported housing units next year and nearly 1,000 more units by 1993. Provision of these services is an essential part of the continuum of treatment for the HIV positive patients, and will result in fewer hospitalizations and nursing home admissions or earlier hospital discharges. We will also need an additional set of alternative care resources, over 1,000 health related and skilled nursing beds, and

home care for over 10,000 individuals, over twice the number that have been cared for in this past year.

Future projections also show a shift in new cases toward the IV drug using population, as Dr. Myers pointed out. This will have special implications for this city where the at risk population is about 200,000, 60 percent of whom are estimated to be HIV positive. Increasing numbers of women and children will be effected, as will low income and minority communities.

There are a couple of issues around specific programs I would like to just touch on. If the public sector continues to cares for this disproportionate share, our ability to provide care for traditional patient population, that is, those people who are uninsured or underinsured, will be seriously compromised. In the current fiscal year, HHC will spend more than \$300 million on services for patients with AIDS, including direct medical care, supplies, social services, health education and salaries, 43 percent more than was spent in fiscal year 1989, and an increase of more than \$286 million since 1985, fiscal year 1985. At Bellevue alone this past year, the direct expense was \$45 million.

In ambulatory care, we estimate that for every inpatient with AIDS, we are providing services for five outpatients. HHC will provide service to 8,000 outpatients this fiscal year across the whole system for a cost of about \$35.8 million. This is an increase of 4,800 outpatients since the previous fiscal year. If we look at the long-term care component, HHC's long-term care beds make up about 5 percent of the city's capacity for this level of care. Yet, we were the first and are currently among the very few long-term care providers in the city providing services for AIDS patients. We have 86 medical long-term care beds and 28 psychiatric long term care beds for AIDS patients. An interesting side light here is if we look at how the physicians practice within our hospitals, we find that those at Bellevue tend to keep our patients a little bit longer in the hospital to ensure their compliance with therapy, rather than discharge the homeless to the street or some other facility where they won't receive the care they need which will result in them returning to the hospital fairly quickly in a more acute state.

The public sector simply cannot continue to bear such a disproportionate share of the responsibility for caring for the HIV ill. The Federal Government must ensure that it is an equal partner with the States and localities in providing for the health care services and needs of this population. The Federal Government must extend Federal Medicaid coverage to single individuals who are HIV ill. The Federal Government must also, therefore, ensure reimbursement for the full cost of AIDS care in order to prevent any financial disincentive for other institutions caring for AIDS patients that might ultimately result in their dumping of AIDS patients on the public providers.

Moreover, the Medicaid inpatient payment rate for patients with AIDS and for HIV positive individuals should be increased for hospitals serving a disproportionate share of the HIV or AIDS patients.

The Medicare and Medicaid reimbursement must pay for the additional cost of treating the drug abuser with AIDS, whether it is in the hospital or in an outpatient setting.

The Federal Government must provide funding to major urban areas to construct and rehab housing units for people with AIDS and to subsidize rents for existing facilities and apartments to keep people in their own homes.

The Federal Government must address adequate reimbursement for the delivery of ambulatory care services for AIDS patients.

Federal Medicaid eligibility for outpatient services should be extended to individuals with HIV related illnesses and disproportionate share hospitals should receive a rate adjustment. The Federal Government should also take a more active role in providing incentives to States to develop outpatient and community-based treatment programs.

The proposed 25 percent rate adjust would dramatically close the gap between what we are currently being reimbursed and what our current costs are to take care of these patients.

Congress should revitalize and redirect, as Dr. Myers pointed out, the National Health Service Corps, an excellent way to provide services.

In closing, Mr. Chairman, I believe we have all come to the recognition that the problems posed for our health care system by AIDS/HIV-illness are inseparable from the problems posed by all the medically disenfranchised. The public hospitals in this country have been at the vanguard of addressing these problems and highlighting the needs for a major reform of the overall health care system. We will continue to press for public policy that assures access to the full range of health care from primary care on through long-term care, equitable participation by all levels of Government, and explicit recognition of the additional stressed placed on disproportionate share providers. Thank you.

[The prepared statement of Mr. Channing may be found at the end of the hearing.]

Mr. SCHUMER. Thank you very much again Mr. Channing for your outstanding and comprehensive testimony. I must say that what you gentlemen have given us is not just a discussion of the needs of the legislation that we are pushing but also an outline of other things that should be done and in that way it is most, most helpful.

I want to give our final witness a little special thanks because he has been instrumental in this effort. We sat down earlier this year and bounced around some ideas that would help New York hospitals and this AIDS hospital impact proposal that is now going through the Budget Committee and then through the Commerce Committee really is a result of my discussions with Mr. Raske. I want to thank him for that. There were a few other people who had some input but he deserves a lot of credit for helping refine this idea. Ken Raske is the president of the Greater New York Hospital Association. The association represents 122 not-for-profit hospitals and long-term care facilities in New York City and surrounding communities. They too, just like the city's hospital system, are doing an outstanding job under very, very difficult circumstances. I should underscore that our worry here is that that outstanding job just can't continue much longer unless there are new resources put into the system.

Mr. Raske, as with the other witnesses, your entire statement will be read into the record and you may proceed as you wish.

STATEMENT OF KENNETH E. RASKE, PRESIDENT, GREATER NEW YORK HOSPITAL ASSOCIATION

Mr. RASKE. Thank you, Mr. Chairman. It is a pleasure to sit before you today to talk about the major crisis that we are facing within the health care system and the role that AIDS is playing in that crisis. We have an awfully lengthy statement that I will summarize for this hearing and highlight just a couple of places that I think really deserve attention.

Mr. SCHUMER. Thank you.

Mr. RASKE. I want to draw your focus first of all to the tracking of the epidemic as it falls within our hospitals. As you have gone through at Cabrini today, a tour of some of the patient floors seeing some of the people affected by this major epidemic, we see in a graphical sense what has happened over the last couple of years in terms of people who are hospitalized within our hospitals throughout New York City Health and Hospital Corp., facilities as well as voluntary. And, today, we are probably around 2,000 patients—the equivalent of probably the total hospital capacity of most medium sized cities in the United States—are devoted to the care and treatment and compassion and care and treatment of our individuals with AIDS and AIDS-related illnesses.

The chart clearly shows that there is no end in sight. The epidemic is just marching on and on and although the best of interventions are being attempted at this particular point, no cure has been found. We pray, though, that someday that that will occur.

In the meantime, gentlemen, we are looking at this epidemic in the context of a very sick health care system, in fact, critically ill health care system. I am pleading before you today for help. The Federal Government must come to our aid. In the absence of any aid from the Federal Government, we will have a partial collapse of our health care system that will ripple throughout rich and poor, young and old, those with AIDS and unrelated illnesses to AIDS will be impacted and we will have a difficult time providing the kind of care that is necessary to those who need care.

Your initiative is an extraordinarily important first step in that direction. I believe that without some additional help from the Federal Government at this particular time that within the year, we will see some of our hospitals close. That is a statement that I have not made before but I believe that the situation in Albany in terms of budget cuts which are being forecasted, I believe, that the situation in Washington with the President's recommendations for major gutting of the Medicare program as it relates to medical education and as it relates to capital, both of which are ground zero in New York City will end up falling on the doorsteps of these institutions and there is no way that they can continue to make it.

Mr. Schumer, in your district and in the districts surrounding you, last week we had a situation that just underscores the point that I just made because, as you know, the State budget has not yet been approved, there has to be an extending appropriation in order to cover the varying payments that are made by the State includ-

ing, of course, Medicaid. We had a situation last week where there was a delay of the extension of an appropriation by three hours on the day that hospitals were to receive their Medicaid checks, and within 3 hours, I received 10 phone calls from hospitals as to where their Medicaid checks were because they cannot make their payments and there are other obligations that they have. Now, that is a very sad situation for institutions as complex as these who have the responsibility of not only caring for people but paying their workers and paying their vendors and paying their insurance premiums and paying, of course, the debt service to the bond holders which help finance these kinds of institutions. So, I submit, gentlemen, that unless we have a major reinvestment in our institutions and an additional source of funding for them, we are going to be in a situation that will go from bad to worse and relatively rapidly.

My sense then is to be very clear with you and that is that the New York City Congressional delegation, you have not asked for this responsibility but it is yours and we in the community so much appreciate the efforts that you and your colleagues have made and will continue to make on our behalf. We need your help, we need the help of your colleagues in the Congress, we need the help of the Administration in both Albany as well as in Washington, in order to turn our current crisis around. I can get into any level of specifics gentlemen that you wish, but I think the sense of urgency is most important and I wish you god speed in getting this bill enacted.

[The prepared statement of Mr. Raske may be found at the end of the hearing.]

Mr. SCHUMER. Well, thank you Mr. Raske first and less significantly for your brevity but much more significantly for the power of your statement. It is terribly disconcerting that everything is coming down on the hospital system at once. You have a squeeze in reimbursement rates both at the Federal and State levels and all of these new responsibilities. AIDS, of course, is the one we are here to discuss today, but there is drug abuse, there is homelessness, there are other problems and as I mentioned, city hospitals are sort of a shock absorber. You have to absorb all of those things and make the health care system work well nonetheless.

The other thing that is so troubling to me is that the health care system is one of the great jewels of New York City. It has always been that way and yet in a few quick years the shine from that jewel could be snuffed out. It would be very difficult to restore it again, so we are going to labor very, very hard to get this initiative passed.

I want to mention one other point that Mr. Channing emphasized. There are two initiatives that I have come up with. One is the hospitals' initiative and the other is an AIDS housing initiative. It is not really the subject of the hearing today but since all three of you have mentioned it in your testimony, I thought I would mention it. I introduced the AIDS housing initiative along with two other Members of the Housing Subcommittee—Jim McDermott and Nancy Pelosi. I am not only on the Budget Committee, I am also on the Housing Subcommittee of the Banking Committee. We put in a bill that would provide \$240 million this year for housing for people with AIDS. It was clear from one of the

patients we visited today that their stay in a hospital bed is prolonged when they have no place to go home. It is not good for them and not good for everyone else who is trying to get into the beds. The AIDS hospital initiative has a quicker timetable but you will be hearing a lot more about the housing initiative. I know that some of the groups in the city have already started making a push for it.

The other point that should be underscored is that this crisis affects everybody. If you don't know a single person living with AIDS, and if you are a New York City resident, it is going to affect you because it is going to put an increased strain on the health care system.

I would like to ask a number of questions. First, Mr. Raske, it was astounding that you said that some of the hospitals would close if nothing was done if the present course continues. Could you elaborate on that?

Mr. RASKE. Absolutely. In the last few years, the hospitals in New York City from voluntary institutions have been racking up extraordinary losses both from an operating standpoint and bottom lines, some of which are captured—individual institutions you have read about. But, as time is going on, we are seeing that no particular progress is being made to help any of these institutions from the standpoint of public policy. In fact, in both Albany today and in Washington within the next few months, as you consider the overall budget, major proposals are being made by the respective Administrations for cutbacks in the Medicaid program in Albany, which could total somewhere around \$300 million, and also in Washington, the Medicare program which could translate into hundreds of millions of dollars, if not approaching one-half billion as it relates to our component. So, if you take a bad situation, you take those two actions that are taking place and without anything coming to positively effect it, you can't help but program destruction for certain segments of our community.

It is inescapable. I don't know what people are thinking about when they make these kinds of proposals. To assume that they can continue to be absorbed in that shock absorber sense that you are talking about Congressman, is absolutely absurd. It would be a physical impossibility to do. So, what we are trying to do at this point is to get the message out to public policymakers and that is look at—we need a hand, we don't need a shovel to dig our situation in deeper.

Mr. SCHUMER. Are you talking about 1, 10 institutions?

Mr. RASKE. It is difficult to actually translate into specific numbers. It is clear to me that it would probably be more than one institution.

Mr. SCHUMER. Can some handle the strain better than others?

Mr. RASKE. Some can handle it better, this is not a universal statement. Some can handle it better because everybody has a different payor mix, has a different ability to withstand these kinds of pressures. Some are better endowed than others, but most of our institutions have no resources other than the payor sources that are presented to them, such as Medicare, Medicaid, Blue Cross, and of course the variety of other so-called self-pay patients.

Mr. SCHUMER. Right. Dr. Myers, you were an expert, of course, on this subject before you came to New York but can you share with us some of your impressions having arrived here? How fragile is our health care system, how desperate is the need for the kind of initiative we are talking about here today?

Dr. MYERS. Well, in the very first paragraph Congressman of the statement that I read parts of to you, I know that New York has by far the greatest burden to face in this epidemic. If you combine the next four cities, you don't even have the New York burden established, and then you have to add that burden, Mr. Chairman, to the current fiscal crisis that we face, not just in the city of New York, not just in the State of New York, but in the Northeast, and then you have to ask yourself what ripple effects will this crisis in the health care have on other ostensibly nonrelated efforts such as economic development. If you are a new major corporation with a new product that you want to sell, maybe you are from overseas and you are making the decision as to where to establish your base, you look at lots of factors—you look at labor, you look at utility rates. But, you also look at the health care system that would be available to take care of the workers that would be manufacturing the product and given the kind of discussion that we have had here today, I would suspect that those investors would want to take a very, very close look at the situation in health care in New York City, as they make those kinds of decisions. You are right, that shining jewel has been there and it is up to us to make sure that that shine stays and we are at a point now where it is clearly at risk.

Mr. SCHUMER. I think we do, as you both mentioned, as Federal legislators, have an added responsibility. In the eighties, the Federal Government was cutting back but the State and city were quite healthy and able to take up a good amount of the slack. Now, in fact, they are going to be increasing your burden and it is up to us to come up with more. I have been concerned about the suffering of people with AIDS for a long time, but one of the reasons I think this initiative is important is it has such an impact on New York City. It is finally the Federal Government doing something to deal with a nationwide problem, but that will have an effect, a dramatic effect on New York City, and that is one of the reasons that we have all pushed it.

Mr. Channing, you talked a little bit about the housing problem. Could you explain to us in specific terms how many of the patients in your institutions have received their care and just stay in the beds a longer period of time because they don't have a place to live?

Mr. CHANNING. It is a particularly important problem for us. We took a look about a year ago, we took a 1-day snapshot of every patient in the hospital. Now Bellevue is a 1,242-bed facility and that day we had a little over 1,000 patients. There were approximately 40 percent of the patients in bed who were construed to be undomiciled or homeless throughout the whole hospital. When we looked just at the psychiatric service which represents another third of the beds, the percentage went up to 70 percent, so it speaks to the greater issue, not just looking at HIV positive patients.

We look today at how the patients are cared for in the hospital. Again, as I mentioned in my testimony, of the 150 or 155 patients we have in the hospital on any given day, roughly half of them are homeless and tend to remain in the hospital an extended period of time. They tend to stay twice as long as those patients who are considered not homeless. They have no place to go, they have no support systems available to them. It puts an increasing burden on the hospital dealing with tremendous pressure at the front end from the emergency room and from the services for other patients. The physicians who are treating the patients are also very much aware and are concerned for the patients' well-being, and tend then to keep the patients a little bit longer. They know if they are discharged from the hospital that there is no place to go, that there is nobody who is going to support them to ensure that they stay on their therapeutic program, that they come back for their clinic visits, that they take their AZT or come in for their Pentamidine program, so they keep them longer. So, when you look at the two populations in the hospital, you see that the homeless population stays much, much longer and tends to be readmitted in the more acute state than those patients who are not. Those patients in the AIDS program who were treated regularly as outpatients and they come into the hospital for significantly shorter periods of time, a little bit more often, but they are more for fine tuning as opposed to providing basic services to them.

Mr. SCHUMER. One final question to all three gentlemen. I think if you could sum up the situation that we have seen today both on our tour and listening to your testimony, if you had to sum it up, would you say, we may not yet be in a disaster, but we will be in one in a very short time unless something is done. Is that fair to state? Dr. Myers.

Dr. MYERS. I would agree with the Chair's interpretation of the situation and would use an analogy that if the New York City health care system is the patient, we are being wheeled right now into the ICU. The question is, Are the life support measures that we hope that you will provide through the Federal Government, going to resuscitate us and get us back to a good state of health?

Mr. SCHUMER. Mr. Raske, would you say we are right at the edge of the disaster?

Mr. RASKE. I would. I believe Mr. Chairman to go one step further that what we will lose here is more than just nameless, faceless institutions and individuals who work in institutions or perhaps even patients. What we are losing is part of what makes us a society. The essence of our intellect, the essence of our compassion, is what separates us from everyone else and once some of this disaster goes on to a certain point, you can never regain it for the investment period is so long that you would have to spend another generation to recoup it, and I worry that some of what we may lose or are losing perhaps even as we talk may never be recouped again.

Mr. SCHUMER. Mr. Channing, would you say that disaster is nigh?

Mr. CHANNING. I would say that it is dawned on us in a very dramatic way and I think, as my colleagues have pointed out very well, that we can no longer be naive about it and we have to act as

rapidly and precipitously as possible, and it extends on through to looking at Bellevue for example as having been in the forefront of a great deal of medical education, and discoveries and delivering services throughout the health care spectrum. These programs are absolutely at risk in the current environment.

Mr. SCHUMER. Thank you. Mr. Scheuer.

Mr. SCHEUER. Thank you Mr. Chairman. You asked a lot of very excellent questions. I would like to hit a point that is an unhappy fact of life for all of us and that is that we operate in an environment with severe constraints on the resources that are available to meet the problems that you gentlemen are outlining. We are talking about in addition to the current cost of health care, due to your predictable increase in AIDS cases, that it is going to raise health care costs exponentially beyond where they are now and you are talking about the need in New York City for the equivalent—one of you said five or six new hospitals a year, a 500-bed hospital a year—I forget which one of you said that, one of you did. And you are talking about the need for new housing. Chuck Schumer is talking about \$300 million for housing for AIDS people. We urgently need housing for AIDS people to get them out of hospital beds where they do not need that level of care any more with the emergency facilities and all of that. But, whether our society now with a President who says, "Read my lips, no new taxes," whether our society is prepared to build five or six new hospitals a year of 500 beds each, and whether we are prepared to build \$300 million worth of housing for AIDS people, to me is very problematical.

We have to measure the needs for additional expenditure on AIDS for the other needs, the competing needs of the health care system. They are there. We are not spending enough on prenatal and postnatal. We are not spending enough on the beginning of life for a mother and expected infant. Many women don't enter the health care system for advice, counsel, treatment, what not, until they begin birth panics and go to the hospital. They haven't had any prenatal care at all, and frequently they disappear from the hospital within hours or a day or two of the time the child is born. So, neither the child nor the mother gets post natal care.

Now, America already spends 50 percent more as a percentage of GNP then the average of the developed countries—of the OECD countries. We spend just under 12 percent of GNP for our health care. This is \$650 billion a year. The average of the Organization of Economic Opportunity and Development is about 6 percent. Japan spends less than 6 percent as compared to our less than 12 percent. They spend one-half of what we spend as a percentage of GNP and they have quite approvably better health care outputs then we do. Life expectancy at birth, infant mortality, longevity, I mean, by a dozen tests, the Japanese people are healthier then we are and they spend half of what we do as a percentage of their GNP so it is not that we are not spending enough on health care. I guess no other country in the world has it quite as badly as we do of AIDS, and we have to deal with it and we have to deal with it with compassion and sensibility and sensitivity.

But, we are not only competing with other health care needs, we are competing with other needs that society has. Dr. Myers, the health care costs of patients in this very hospital suffering from

AIDS amount to about \$950 a day. Right. Now, you are only serving in a Head Start program, one-half of the kids at education risk in this city, and this city does better than any other city in the country. The average for the country is about 16 percent, about one kid out of six or seven gets a Head Start slot and I am only talking about kids who are at urgent education risk, kids from deprived homes who almost are destined with mathematical certainty to fail at school unless they get an enriched preschool experience. Across the country, we are giving maybe one kid out of six or seven that kind of treatment. In New York, we are nobly and to your credit and to the credit of everybody involved at the city and State level, we are giving 50 percent of those kids a Head Start slot but we are also denying 50 percent of those kids a Head Start slot. The cost is anywhere from \$4,000 to \$5,000 or \$6,000 a year.

Now, for every week that this hospital takes care of an AIDS patient, in effect, that is the money that would provide a 1-year slot for an urgently needful 3-, 4-, or 5-year-old, that we are not providing a head start for. So, what I am saying is that these extra moneys have to compete with other needs within the health care system and other needs of society and I have only talked about one little slice of the education need. The need for kids from deprived homes to have a head start experience. I am not talking about the full array of infrastructure needs for roads and bridges and tunnels and water systems that are at the point of collapse. I am not talking about a health care system that is depriving 31 million people of access to the system. That has to be dealt with. I am not even talking about the need in the health care system for long-term care for the elderly.

What I am saying is that the cost of taking care of AIDS patients, compassionate and compelling, and heart rendering as they are, must take their place along with a lot of other needs of society. They can't be placed in some kind of priority position ahead and above and more important than other health care needs and other society needs.

So, now I get down to the prospect you raised by all of you that we need a lot more housing to take people out of hospital beds, AIDS patients, and we need a lot more hospital beds. Now, I am asking you to think creatively, scratch your minds, and let us know if there aren't some alternatives to this expensive new construction that you are speaking about, alternatives to the \$300 million worth of new housing, I presume, Mr. Schumer.

Mr. SCHUMER. Rehab.

Mr. SCHEUER. Rehab, that's it. Have you thought through the modality of treatment that could be used, let's say if you put AIDS patients, move them out of hospitals, into existing apartment or existing single family homes. The traditional white elephant. The large home that now, perhaps, one surviving parent is living in, the kids are all gone and the parent is an empty nester, that home is a burden. They tend to move out of the homes and go to Florida or go to a senior citizen home—is there some way we could use a large home with six, seven, eight bedrooms—is there some way we could use existing—take over an existing apartment house in terms of new hospitals. I remember the years when we talked about

downsizing New York City's hospital beds by about 5,000. Ken Raske, it wasn't all that long ago was it?

Mr. RASKE. No, it wasn't long ago.

Mr. SCHEUER. Pardon?

Mr. RASKE. The planners were forecasting that in the early eighties.

Mr. SCHEUER. Yes, that we were going to downsize our hospital system by 5,000. Aren't some of those hospital beds available in perhaps older hospitals that could be rehabilitated a little bit? Aren't there some hospitals that have been abandoned, perhaps in the suburbs or outside of New York City, where we can bring them back into the health care system and design them as AIDS institutions? In terms both of hospital beds and in terms of housing, post hospital care, aren't there alternatives to new construction? Aren't there ways that we can find those resources within existing structures that perhaps have been phased out of the use for which they were originally designed? Can't we bring them back into the health care system, fixed up, adapted, proved, but made available at a very, very much less expense than a new facility?

Mr. RASKE. Well, the answer is yes to some degree but the biggest problem isn't the physical structure, it isn't the buildings, the bricks and mortar that constitutes the greatest impediment. The greatest impediment to any significant response from a supply side, either nursing home or hospital or some variant of the two, is adequate supply of trained, competent individuals to staff those beds, especially professional nurses, but not limited to professional nursing. And we are currently in a major personnel shortage throughout New York City, but this is true across the United States generally, but in the case of nurses specifically, we need probably about 15 percent more nurses than we currently have and that is for the current level of budgeted activity, let alone any additional activity, and the problem is Congressman, that the only way in the long run in order for that situation to turn around—it has nothing to do with all of the initiatives such as programs and education and the rest of that, it is going to be a market correction which is going to occur because wages have increased sufficiently enough to bid in additional people into the labor market, and that is the way it happened with teachers, it is the way it happened with engineers, and that is the way it is going to happen with nurses. But, when I say that, I just said a billion dollar solution.

Mr. SCHEUER. Mr. Raske, we have a desperate national nursing shortages for the non-AIDS health care community, correct, so one wonders whether—how you are going to find the additional nurses you are talking about. Is it possible that the task, the health care tasks of caring for AIDS patients can be redefined so that many of these functions can be carried on by paraprofessional people, nurses aides, nurses assistants, health care aides. There are many areas in the education system and the law enforcement community and housing where what had been formerly conceived of as professional jobs, have been redefined and people with less than college educations and in many cases less than high school educations are given 6 months or 1 year of training and they can function very well providing many services—not all—but many services that formerly had been only carried on and provided by professionals.

Couldn't you redefine many of the functions that nurses now carry on for AIDS folks and enable paraprofessionals perform those jobs under the supervision of a health care professional?

Mr. RASKE. There is no question. To some degree, Congressman, that can be done and it is actually going on right now. The problem is that this health care system, particularly on the hospital side, is a very sophisticated system. As you went on your tour, you could see the high tech intervention that is necessary in order to provide the best in patient care and in the same sense that you say that, you also require highly trained and skilled professionals to do that, more than just a couple of months of on the job training, sir, in order to really do the job properly.

Mr. SCHEUER. Six months to a year?

Mr. RASKE. It could be a long time for the right kinds of individuals in terms of how they are doing and what they are doing at the bedside.

Mr. SCHEUER. Can I ask briefly either of the other gentlemen are there any ways we can devise alternative modes of health care for AIDS patients, both physical structures and actual treatments at less cost than what we are doing?

Dr. MYERS. I think you have already heard it stated clearly Congressman, that there are patients that remain hospitalized for whom the level of service available in the hospital is not necessary any longer. I think the first step in trying to accomplish what you stated is to find places for those patients that no longer need the high tech care that is available, such that that can be most appropriately to utilize.

Mr. SCHUMER. To just augment what Dr. Myers said, in the AIDS housing proposal that we are talking about, which is rehab, not new construction, the average cost is \$130 a day. The average cost for a person in a hospital bed is, I think, nationally roughly \$700 a day. There are solutions that would ultimately save money. We have just got to start pushing them through.

Dr. MYERS. Congressman, in your earlier remarks though you brought up a very interesting choice. The choice that now many of us in public health are being forced to either directly or indirectly to sometimes consider and that is between choosing AIDS or infant mortality.

Mr. SCHEUER. Right.

Dr. MYERS. Choosing between one disease or another and increasingly we are being asked to do that. Those are questions that people like me are being forced to consider. I would rather the U.S. Congress chose between one more B-1 bomber or one more armed forces base that could be closed and then make those kinds of choices so that I am not forced to make the choices that you have described that are on my plate.

Mr. SCHEUER. Well, you can be sure that Chuck Schumer and Jim Scheuer are at the vanguard of making those kind of tough decisions and making sure that we have the piece dividend soon rather than late that can be applied to these urgent social needs.

Mr. SCHUMER. Thank you Mr. Scheuer, and I want to thank the entire panel. It has been an excellent discussion. Thank you.

Our second panel consists of people who are on the front line in the battle with AIDS in our hospital system. We will hear personal

experiences of people who are living with AIDS, as well as some of those who strive to give medical care under sometimes extremely difficult conditions. We will hear from Robert Santoro, Ron Smith, and Steve McCoury. These are people living with AIDS and they will share their experiences, both positive and negative in receiving care at New York hospitals. We want to thank them for their willingness to speak out openly. We will also hear from Gloria Bailey Campbell who is a nurses aide and provides care to people living with AIDS at Bellevue Hospital. She is the chapter Chair of Bellevue Hospital Local 420. And finally, we will hear from Dr. Brian Saltzman, a physician at Beth Israel Hospital. He will share his experiences working with people with AIDS.

So, if you would all come forward. There is a fifth witness who wasn't sure that she would come forward because she requested anonymity. If she would like to come forward, we welcome her, but if not, we understand. Thank you very much.

The only thing I would ask all of the panelists—and I wasn't terribly rigorous with this and I should be because we are running considerably behind schedule—is to please limit your testimony to approximately 5 minutes, it would be helpful. Since we have a very large panel, maybe one person could augment the next person's experiences. If that is all right I would ask for cooperation and I will gently tap the gavel at the 5 minutes. I am a new Chairman and I am not very good at that so you will have to bear with me.

Our first witness is Steve McCoury. Is that all right Mr. McCoury?

Mr. McCOURY. That is fine with me.

Mr. SCHUMER. Go right ahead.

STATEMENT OF STEVEN MCCOURY, PERSON LIVING WITH AIDS

Mr. McCOURY. First, I am a little nervous so bear with me here.

Mr. SCHUMER. I know. I have been at the other end of that table and I have been nervous too.

Mr. SCHEUER. Just imagine that we are all sitting in your living room and we are shooting the bull so to speak.

Mr. SCHUMER. Something at least people at this end of the table are very good at.

Mr. McCOURY. I am a person living with AIDS. I was diagnosed with AIDS in 1987, in December 1987. In the last year, 1989, I was in the hospital five times at a cost of approximately \$200,000 for the year with doctors and medication and hospitalization. The last time I was in the hospital was in December until February here at Cabrini and when I came to the hospital I had pneumonia, pneumocystitis, and it took about 2 hours in the emergency room to be seen until I had a seizure in the emergency room. There was no gurney available.

Mr. SCHEUER. No what available?

Mr. McCOURY. No gurney or stretcher available for me to lie down. My only alternative was to lay on the floor in December in the emergency room.

When I was taken into the emergency room, it took 4 days to get a bed upstairs. I was in a room with approximately 15 other people. They didn't know if it was PCP pneumonia or if it was TB or if

what I had was contagious or not—not for the first day or so. So, I was putting other people at risk by being in such a large room.

Then, when I did go up, I was put on a floor that is not designated as an AIDS floor which means that they don't have the appropriate nursing care on every floor. On the 11th floor of this hospital, it is designated as the AIDS floor. It is double nursing, you get better treatment, if your bed needs to be changed, if you need medicine right away, if you need to see the physician—you get priority care.

When I was going to be released from the hospital finally on February 17, I required nursing care at home and my insurance, even though it is very good insurance and I work for a very good company, unfortunately would only pay \$25 a day for a nurses aide to be with me which was absolutely essential to my being out of the hospital.

The actual cost was \$1,700 a week and that was for a 5-day week, 8-hour—no, I'm sorry, a 12-hour shift, which I don't have that kind of funding behind me to pay for that. So, I am still at this point unclear as to how I am going to pay that bill.

I just became eligible for Medicaid as of March 1 after 2 years. I talked to my doctor and he told me that he couldn't accept Medicaid payments because if he did, he would be limiting what he could charge me so he suggested that I pay the money up front and Medicaid reimburse me and then I submit the rest of my bills to my insurance company which will pay 100 percent, which is true, but my doctor bill is \$150 a week to see my doctor which does not include medications. AZT is about \$761 a month. Zovirax which I am required to take is about \$300 a month, and I get \$658 from S.S.D. a month. My rent is about \$850 a month. Food, someone to clean the house because I can't smell the fumes any more, like bleach or Comet—I am just incapable of handling that—all of those expenses add up and I don't have that and I am fortunate. I have disability insurance which supplements my income and I have a good health care insurance from my employer. The vast majority of AIDS people in New York don't have those resources to rely on and besides the stress of just having the disease, to have to worry about where the money is coming from to deal with this to be able to be an accountant, to have a full time job, since submitting bills to different insurance companies and doing the redtape to get the funding that you need, is almost overpowering, especially when a lot of people with AIDS had dementia—they can't make decisions by themselves and there are times when I am under so many drugs, I don't recognize people. And, so for me to get the appropriate care is almost impossible at times.

I think I basically have covered the areas to make you have some insight as to what it is like on this side and with my life. Thank you very much for the opportunity to come before you.

Mr. SCHUMER. Well, thank you for your willingness to come forward because it brings the issue to life. Your testimony is very helpful to us.

Our next witness is Ron Smith.

STATEMENT OF RON SMITH, PERSON LIVING WITH AIDS

Mr. SMITH. Thank you. I also thank you for this opportunity. I speak as a primary care partner for the last 3 years. My life companion died in February, in the middle of February, and I am also HIV positive and I also, like Mr. McCoury, we have, I think in the realm of people with AIDS and living with AIDS, a fairly good situation. We are fully insured. My friend was able to get Social Security, two-thirds of his salary, and his company voluntarily paid the one-third remainder while he was still alive.

Mr. SCHUMER. I think the name of that company deserves credit.

Mr. SMITH. Well, the name of the company is Seatco (phonetic). Because of that, we were able to manage better than most people as far as paying our bills, but the expenses were phenomenal and we didn't have much other support besides.

I would like to go into the fact that because we were fully insured, and because that we were advocates in the empowerment of learning about AIDS, treatments of AIDS, different infections, political support groups, getting the best doctors, using the best hospitals, we ended up going to what we thought were the best facilities in New York City and I still believe they are, but we had experiences at these facilities which, in some ways, are not considered the best situations and for us were very crucial crises at the time. Roosevelt Hospital in November 1987, my friend had an appendectomy and peritonitis, a burst appendix. We were caught and stuck in the emergency room of Roosevelt Hospital for 22 hours before we were able to have an operation done for the removal of his appendix. The reason that we were told unofficially and not officially was that there was no surgeon there that would operate on an HIV infected person. This was November 1987.

Luckily my friend was otherwise healthy except for being diagnosed earlier that year and was able to recover from that situation. I want to also mention that at that point, there were gurney stretchers—as Mr. McCoury mentioned before—stretched all over the emergency room and we were stuck in an examining for that 22 hours with my friend on a gurney stretcher, and he was in extreme pain with this peritonitis.

The other situation I want to talk about is that in December 1989, at NYU Medical Center, my friend was rushed and again we had to stay in the emergency room at NYU which is noted to be a very good institution for AIDS for 24 hours. He had a bowel obstruction due to adhesions from the appendectomy that he had. In a much weaker state, because at that point he had M.A.I. tuberculosis which is a very devastating infection on the body—it occurs with AIDS. After 24 hours, we finally got a hospital bed and he was admitted, and that is because they deemed this a surgical procedure and a top priority.

There were other people, other PWA's, in the area, in the examining room, that we were in. Two other people, one of them had told me that he had been waiting there for 4 days, another PWA, to get a hospital bed at NYU. He had severe hepatitis and wasting syndrome.

I want to say that NYU has a policy or had a policy of giving all PWA's private rooms. I think this is very sensitive to health care

partners to be able to stay with the person that they are treating, but otherwise I think that the fact that we have this problem with other PWA's in the emergency room and not being able to get into the beds in the facilities is the issue that we are dealing with here at this point.

I want to mention one other thing that in February, my friend was readmitted to NYU Medical Center and I think there was—we had a problem with staffing and with the medical staff at that point. There seemed to be an attitude problem and I think it has to do with the fact that there is a shortage of medical staff. My friend was kind of in a terminal state at that point. He had an infection, he had to have an emergency operation, and I think that the surgical staff at that point—he had a lot of difficulty trying to get information and ask questions about his condition at that time.

I want to also mention that during our stay at the last time at the hospital, I, as a health care partner, stayed in the room with him and the nurses aides would ask me to take his temperature, his rectal temperature, they would ask me to help clean the floors, they would ask me to help make up the bed. He was incontinent at this point. If I had gone to work for the day, I would come back and the bed would not be made.

Mr. SCHUMER. Was it because they were so overworked?

Mr. SMITH. Well, overworked and also there were still remnants of paranoia I think with some staff, even in these good facilities.

I also want to mention one more thing in that my friend had a Hickman, which is an IV used in the chest and it is just one example of—the surgical staff there gave us a very hard problem about giving him intravenous feeding at that time. They would not do it through the Hickman, they insisted of doing it through his windpipe, and when they finally pushed this tube up his windpipe, the next day it fell out, and they felt that the staff was rather insistent on doing this other procedure without listening to what the patient really wanted or consulting with the patient enough to get a different view. This was also the choice of the medical doctors. They have the surgical doctors and the medical doctors, and they would have preferred to give him feeding through the Hickman rather than through the tube.

Mr. SCHUMER. Thank you Mr. Smith. We appreciate it very much.

Our next witness is Robert Santoro.

STATEMENT OF ROBERT SANTORO, PERSON LIVING WITH AIDS

Mr. SANTORO. My name is Robert Santoro. I am a person living with AIDS.

I was hospitalized myself once only 3 years ago and my personal experience was adequate at that time. I was in an AIDS ward where the nursing staff was, I would say, 50 percent of them were sensitive to the specific issues, and 50 percent knowledgeable to the kind of care that was needed for situations that hadn't previously been dealt with on a regular basis.

Since that time, I have been involved in primary care, assistance of I would say an average of five people or more per year, where I have been there day and night in the hospital for a period of a

week or more and I have seen—I have witnessed some practices that were just horrendous.

I have seen nurses attempt to do procedures on someone who was physically incapable of handling it where—I have seen a nurse do something to a friend where I asked her not to and she said, "No, it was standard procedure" and, in fact, put him into a situation of severe cardiac arrest, which was unnecessary.

I have seen an insensitivity to using drugs. A friend of mine is now in the hospital where 2 days ago he was using antibiotics that he developed an allergic reaction to. They used the same antibiotics the next day and he nearly died because of it.

I have taken part in trying to help someone who was in an emergency ward for several days where their condition was that of running very high fevers and something as simple as using ice packs to get the fevers down or a position that we had to fight for to do because we were told that the doctor didn't prescribe ice packs. They have used Tylenol to try to get a fever down where the doctor said—he explained it to the staff not to use that. I have had to fight with hospital staff to be allowed to stay in the room because I was not a family member, and there was not an adequate amount of nursing care available to handle the situation that needed constant attention.

I have seen the undo amount of stress and anxiety in patients because of the lack of available nursing care, and the lack of acknowledgement of the people around that were there willing and ready to help and had enough of a layman's knowledge to be assistant—turned away constantly. The situation is ludicrous to have to constantly demand to speak to the nursing staff in charge or people that can make decisions, just to be present in a room. I have seen nurses come into a room where the doctor had sealed off the door to an adjoining bathroom between rooms because the patient in the next room was still in a contagious level of TB, and advised his patient not to use the facilities and a nurse would come in and take the tape down and the doctor would reinstate his orders, and the next day the exact same personnel would do the exact same procedure—go into that facility and just rinse off the thermometer and ask him to use it and he refused, and his personal physician told him himself—take your own temperature, you know how to do it.

There are situations too frequently where someone is placed in a room or a ward where there are more than one person that are known to be contagious and they are allowed to just be in the same area and space where they can also pick up another disease, another opportunistic infection, which could be easily avoided.

Mr. SCHUMER. Thank you Mr. Santoro. Isn't it possible that some of the things you mentioned, the hospitals may have had liability problems with? I don't know the rules, but if they allowed you or someone else with the best of intentions to help and something happened—so I don't know if that is the case but it is something to think about.

Mr. SANTORO. I think maybe what I was trying to say is that because we are not a direct family member—

Mr. SCHUMER. I see; that is different.

Mr. SANTORO. Yes.

Mr. SCHUMER. Before we hear Dr. Saltzman and Ms. Campbell, we have a final witness who is part of the panel who wishes not to use her name. Please proceed as you wish.

STATEMENT OF JANE DOE, PERSON LIVING WITH AIDS

JANE DOE. I was diagnosed in 1987 having AIDS. What I really want to talk about—I have been into the hospital quite a few times because I have other medical problems also, but I was just in the hospital in February and there wasn't any room in the unit, so they placed me on a regular floor, an isolation room, and the way that I was treated there was inhuman.

The dietician wouldn't bring the food into the room, it would stay outside the door until someone decided to bring it in. The room was not cleaned because the janitors, or whatever they call themselves, refused to come in the room because they had the sign of isolation. But, I went in there, they thought I had—

Mr. SCHUMER. This was 1987?

JANE DOE. No, this was in February of this year, just passed, and they wouldn't clean the bathroom. Everyone refused to come. There was another person in the room with me also, and they refused to come and to attend to us properly and the most tragic thing that really happened to me, my blood sugar went up and I had to have a CV line which I had before so I know the procedures, and they didn't make no effort to take me someplace else private. They did the procedure in the room and the pain was so—they didn't give me nothing to kill the pain and it was so tremendous until I blacked out. I woke up, my feet, my legs were bound and I had to beg, you know, begged to be turned loose, nobody would turn me loose, so I came out to restrain myself—I kept pulling until I took it away myself.

But, what I am trying to say is the overcrowding in the STU unit and the training of the staff, I mean, if you are not sure what a patient has or if it is contagious, the staff should be trained well enough to know that if they go in with masks or gloves—they are allowed to go into the patient rooms to give them the care. My bed wouldn't be made for 2 or 3 days. The floor—my family complained, until someone outside the hospital came in to complain. It took me about 4 days to even get a blanket for my bed.

What I want to say is that it is terrible, even though we are suffering with the illness ourselves, but I don't think we should be treated as second class citizens.

Mr. SCHUMER. Thank you, thank you very much.

Our next witness is Gloria Bailey Campbell who is a nurses' aid who provides care to people living with AIDS at Bellevue.

STATEMENT OF GLORIA BAILEY CAMPBELL, NURSES' AIDE FOR AID'S PATIENTS, BELLEVUE HOSPITAL

Ms. BAILEY. Thank you. I am Gloria Bailey Campbell. I am a nurses' aide and a chapter chairperson with the Local 420.

I had worked with AIDS patients and the concern that I have is why I asked to come here today. They are human. We are not here to judge, we are here to do bedside nursing and give them the health care that they need. But, what I could say, we don't have

enough stretchers, we don't have enough nurses, we don't have enough doctors, and these people need psychiatry to come and help their need plus social workers, to be there, to help them.

See, not only are they sick, they need the security that someone cares, the understanding, and to see and hear what I have heard from some of the testimonies today is very disturbing to me because they are human beings.

In the health care system, we are here to provide the best. When they are being closed—the first help—say we did not need the nurses for Bellevue School of Nursing, Harlem School of Nursing, Lincoln—I at the time was a chief steward and I spoke up. I said, "You are doing wrong. Leave the schools open so we could train our professional."

Mr. SCHUMER. We are paying the price now.

Ms. BAILEY. You understand. I am a nurses aide. I was going to school because healthwise I had to come out, but I was still a very concerned worker because if you could make one patient happy in 7½ hours, show that love, show the dignity, because everybody has dignity, and should be treated as a human being.

We should be able to be professional whether we are nurses aides, doctors or what. We should go near a patient and give them the most dignified until the last. Let's not judge, we are not God, but give these people the love unto the crisis and to the end.

What we do need, which was stated by Channing, that is my executive director at Bellevue, we are not only thinking about the health care of AIDS, but we need to concentrate on the homeless. We should have accurate funding, and that is why I am asking. Congress should be able to give us Federal money. Somewhere in this life these people have worked with dignity, and they must die with dignity. That is all I am asking for because I feel the need got to get to our main people that is in the mainstream that is taking over our lives.

Somewhere, somehow, they have worked and have contributed to the society, so now they are unable—our society, our Congressman and our leadership in this country. We should get together and allot this money for these people. And I want to say I thank you that I come here today to express from the bottom of my heart the dignity that I think these people should have had, and God bless you all.

Mr. SCHUMER. Thank you Ms. Campbell for your moving words. Our final witness is Dr. Brian Saltzman. He is a physician at Beth Israel Hospital and works with many PWA's. Dr. Saltzman.

STATEMENT OF DR. BRIAN SALTZMAN, BETH ISRAEL HOSPITAL

Dr. SALTZMAN. Thank you Mr. Chairman. I have had a broad exposure to the care of HIV-infected individuals since the initial descriptions of the syndrome, AIDS, in 1981, that has been at Montefiore in the Bronx where you dealt primarily with an IV drug using, black and hispanic population, about 25 percent women at NYU and Bellevue, and now at Beth Israel. And, in that 9 years, there have been really significant advances in the care of HIV infection, but these advances have also placed additional stresses on the health care system.

Initially, we described HIV infection using an iceberg analogy. We referred to it as the iceberg concept of disease where the tip of the iceberg representing the smallest proportion of people was that visible group with full blown AIDS. However, now, studies have shown that even people below the water line, people without clinical symptomatic HIV disease, need to come into the health care system and obtain medications early to prevent the progression of disease and this has really stressed the system because we have more patients entering at the primary care level. All people with risk exposures need to be tested and so we need more confidential testing centers and anonymous testing centers. All HIV infected individuals will require periodic immunologic evaluations and then, as I mentioned, early intervention with antiviral therapy and pneumocystis prophylaxis for those who need it.

So, our primary care system is stressed. General medical, pediatric, and prenatal care, and we need more allocation for primary care in the community settings, in hospital based clinics, and another place that we perhaps can deliver primary care to a large infected population is in the methadone clinics which may be a site for enriched primary care delivery.

HIV infected individuals need access to medications, both approved and investigational. Investigational at medical centers and hospitals, through the NIH and through drug companies sponsor trials, and also in appropriately designed community based trials. These medications include AZT, pneumocystis prophylaxis, Interferon, DDI, and other investigational agents.

I would like to point to ADAP, the AIDS Drug Assistance Program of New York State, as an exemplary program that assures that working class HIV infected individuals can obtain the needed medications. We stress that funds be allocated for the continuation of this program and for the institution of similar programs in other areas.

For patients with symptomatic disease, the problems and their needs change. Of course we have the intermittent need for acute hospitalization as has been mentioned. There is an urgent need for expanded home care services. Included in this is the once again, the need for access to medications, now different medications, generally also extremely expensive and frequently administered by an intravenous route, once again, requiring home care.

You need alternate level of care facilities as mentioned before with increased need for nursing homes and residences because one of the problems that has been cited has been prolonged delays in getting a hospital bed in the emergency room and what you have is an inpatient gridlock and if you can move people out into long-term care facilities, that will facilitate moving people with AIDS and with all other diseases into the acute care setting when they need it.

So, in summary, some of the needs are continued funds for educational efforts to stop transmission of HIV, rapid access to drug abuse treatment, additional funding for outpatient primary care services, creative efforts to attract and maintain care providers, nurses, nurses aides, physicians, perhaps as Dr. Myers mentioned through the National Health Service Corps and also using service as repayment for student loans. Funds to continue and expand pro-

grams such as ADAP, Home Health Services, and housing and long-term facilities, as I mentioned. Thank you.

Mr. SCHUMER. Thank you Dr. Saltzman and let me say two things to the entire panel here. First, as I mentioned after Mr. McCoury testified, this is extremely helpful for us in conveying tangibly the problems and realities people with AIDS face. To understand these problems concretely is more powerful in a sense than the abstract, so your being here is very, very helpful and believe me, I am going to try to get everyone of my colleagues to read the record of this testimony so that your words may actually have an impact.

The second thing is that just seeing you and hearing you, urges me further to do as much as I can both to find a cure for AIDS. You said it Ms. Campbell, we need these people. This country needs people like the people here. I want to thank each and everyone of you for coming.

On our third panel we will hear from the advocacy and labor groups. The witnesses who will come forward are Debby King, Kathy Schrier, Robert Peterson, and Mike Wiggins. If they are still here, come forward.

We now have three of the witnesses here. Let me first say that these are people from labor and advocacy groups. I apologize to everyone about the time. These hearings always go longer than we had intended. I know we had told people we would be finished by this time and people have other appointments and I understand that. Unfortunately, the tour and some of the testimony did take longer than anticipated, but I think it is worth it so I appreciate your waiting.

This panel will describe the difficult circumstances faced by those who work with people living with AIDS and those who themselves are PWA's. We have Debby King who is the executive vice president of Local 1199 of the Drug, Hospital and Health Care Employees Union. Local 1199 has 85,000 members mostly in voluntary hospitals. I have worked closely with Local 1199 on a number of issues including this one and I know that they do great work. For this panel as with the others, statements will be read into the record. We ask you to adhere strictly to the 5-minute rule if possible. I know you have a lot to say so try as I introduce the next witnesses to just summarize what your most important thoughts are but the record will contain your whole statement.

We also have Robert Peterson, policy associate of the Gay Men's Health Crisis, someone I have come to know a little bit. He will describe experiences of GMHC clients in receiving care and make some suggestions for improvement. I would ask you to focus on the suggestions as we had a very powerful group of witnesses before. We also have Kathy Schrier, who is the director of the education department for District Council 37, AFSCME, AFL-CIO. District Council 37 has 27,000 members in public hospitals throughout New York City. Our first witness is Ms. King.

STATEMENT OF DEBBY KING, EXECUTIVE VICE PRESIDENT,
DRUG, HOSPITAL AND HEALTH CARE EMPLOYEES UNION,
LOCAL 1199

Ms. KING. My union, Local 1199 of the Drug, Hospital and Health Care Employees Union is the country's largest local union representing health care workers. Our members are confronted by AIDS everyday both in their communities and on their jobs. Discussions of the strains of the AIDS crisis is imposing on our city's hospitals usually focus on the increased demands on the system, the need for more beds, the high cost of medical interventions needed for AIDS patients, et cetera. Discussions of the epidemic focus less often on the problems faced by health care workers, those who are the front lines of delivering the care.

I want to tell you today that these workers need help to do the job that they want to do and that that help requires dollars to finance the following: More staff in the form of funding for more positions; competitive salaries to recruit and retain workers because we already have a shortage in these jobs and the shortage is getting more acute; support services including counseling and stress reduction programs for people who are working with AIDS patients; training to reduce the risk of infection and purchasing of new equipment and implementation of new work methods to reduce the risk of infection.

Caring for AIDS patients well is labor intensive as you have heard from many of the people who have spoken. We have meetings with registered nurses, social workers, and others, who talk about their dedication to the patients, but who are totally burnt out. They cannot do the job that they want to do and so we have a situation where people who are ready in shortage jobs are leaving because they are there to care and if they cannot deliver that care they don't want to be there. Nurses frequently tell us horror stories of trying to care for several ill patients at once and the frustrations when patients deteriorate or even die because of lack of staff.

Similarly, social work is an area where there has been declining support from the health care system as budgets have been tightened. Again, I have gotten telephone calls from people who say they are working until 8 or 9 at night on a job that is supposed to end at 5 p.m. They are not getting paid for it, but they cannot spend 15 minutes with someone who has just been diagnosed with AIDS and go home. But, then what happens? People can't take it so they leave the health care field. More positions are desperately needed. We can't just let health care workers be chewed up and spit out.

The financial cost of protecting workers against getting the disease on a job will be high too. Specifically, I want to talk about two aspects of these costs. The direct cost of protecting workers against the risk of infection and followup costs for workers who may be exposed to the virus. AIDS infection on the job is a serious danger for health care workers and it requires a serious response. Not long ago, we all heard about the case of Dr. Veronica Prego, but there are many, many more people, unfortunately, who are in that situation. The U.S. Center for Disease Control has found 165 health care workers who are infected with AIDS despite no histories of high

risk behavior. We estimate that health care workers are roughly 2½ times as likely as other low risk members of the general public to get AIDS. That is a pretty high risk.

Helping these workers avoid AIDS on the job will cost a lot of money, for protective equipment, training and changing hospital procedures. Since AIDS spreads at work by contact between blood and body fluids and broken skin or mucous membranes, members must avoid contact with these fluids. The problem is made much more complicated by the fact that most of the people carrying the AIDS virus haven't been diagnosed so that means that these procedures have to be used on all patients—universal precautions.

The first step in implementing universal precautions is providing the right protective equipment to workers exposed to blood and body fluids. Sturdy gloves, boots, gowns or masks, when necessary.

Mr. SCHUMER. Do most provide that?

Ms. KING. A lot of hospitals do. But we find situations where there are gloves provided, but they run out or they don't fit or they rip.

Much of the equipment will be disposable. All of it will have to be changed frequently. Sometimes with each patient, sometimes when it is soiled with blood. The costs are considerable.

Real protection against AIDS will also require far-reaching changes in hospital procedures and equipment. Many institutions have already made the easiest of these—providing solid disposable boxes for sharp objects, but that is far from enough. It will be necessary to purchase medical equipment, redesigned to minimize the possibility of accidental sticks or cuts. For instances, scalpels with built in sheathes like Exacto knives. The principle of universal precautions requires using this new equipment on all patients and as I said, that is going to be expensive but it is an expense that we need to make. And, in some cases, procedures will have to be changed. For example, right now, many laundry workers stick themselves with needles because laundry is sorted before it is sterilized. We are recommending that laundry be put in bags and be sterilized first and then sorted.

The opportunistic diseases which strike AIDS patients are also imposing additional infection control costs on health care institutions. To give just one example, the spread of TB among AIDS patients has lead to its spread among health care workers, with three cases recently reported among our members in one ward, in one hospital. Taking the appropriate precautions, respiratory precautions in this case, such as surgical masks, isolation, et cetera, will also represent a financial burden.

I am stressing the financial burden rather than the human cost because we are talking about the need for more money into the system. Also, workers need to be trained and I was very distressed to hear the woman's remarks about the kind of care that she got in one hospital—lack of care that she got. Our union is very dedicated to seeing that that does not happen to patients. But, there is a need for people to be educated and for there to be, in fact, reasonable precautions so that people do not feel that they are at risk.

Even the best precautions unfortunately are not fool proof. So, hospitals will have to deal with workers who have been exposed to AIDS and other diseases that are spread the same way. In the last

3 weeks, we have had two lab workers who were working with AIDS infected blood and the vials broke and they are both now being treated with AZT. We have asked the hospitals to provide them with counseling. Again, AZT, expensive medication, counseling expensive.

Based on the CDC guidelines, Local 1199 has developed a 10-point program outlining what health care institutions will have to do to protect their workers from AIDS. It includes training, refresher courses, counseling and followup treatment for exposed workers, testing them and confidentiality, purchasing safer equipment, needle disposal boxes, gloves as required and widespread dissemination of infection control information and post exposure followup policy. This is not a mere wish list that the union or the workers are coming up with. This is what the Center for Disease Control says is reasonable and it is likely that OSHA will also be promulgating guidelines along these lines. But, paying for it, putting those precautions into effect and those procedures into effect is going to be costly.

We welcome your initiative and want to say that our members are presently under a great deal of stress doing the best that they can to care for our AIDS population. But, that we need more people and we need more resources in order to do the job that we want to do. Thank you.

Mr. SCHUMER. Thank you Ms. King, we very much appreciate your being here and your leadership on all of these health care issues. As I say, 1199 has been terrific.

We have been joined by a fourth witness who I will introduce when it is her turn to go. Our next witness is Robert Peterson. Welcome, and your entire statement without objection will be read in the record and again, please adhere to the 5-minute rule.

Mr. PETERSON. I'll keep it to 5 minutes.

Mr. SCHUMER. Right, if it is possible. I know it is hard.

Mr. PETERSON. Ring the bell if I go over. It is designed to be 5 minutes.

STATEMENT OF ROBERT PETERSON, POLICY ASSOCIATE, GAY MEN'S HEALTH CRISIS

Mr. PETERSON. My name is Robert Peterson and I am a policy associate at Gay Men's Health Crisis. I would like to start off by again thanking you for coming to meet with the Committee for AIDS Funding in December to outline and educate us about your housing initiative and we have been educating the public officials in New York City since then and we are glad we are able to participate in recent hearings.

GMHC is the Nation's oldest and largest community based AIDS service, education and advocacy organization. Since our beginning in 1981, we have directly served over 8,500 people with AIDS or AIDS related complex. We have answered 300,000 calls for information on our hotline, distributed 3 million pieces of lifesaving information. We have trained thousands of health and mental health providers. We have prevented hundreds of evictions and legal job terminations.

The vast majority of our work has been done by volunteers. We currently have 1,700 volunteers giving over 10,000 hours of work each and every month—lawyers, social workers, therapists, cooks, office workers and nurses.

I speak to you today as a representative of dozens of community based AIDS service organizations in the city providing psychosocial support counseling, case management, food programs, legal and financial advocacy, in other words, to help people through the maze of Federal, State and local entitlement programs, and advocacy for HIV ill people and their families, families of choice. Prevention, education and medication information and public campaigns targeting specific populations such as gay men of color and adolescents and women are also programs that we provide.

I am here to tell you that while we fully believe in the public/private partnership in the Nation's war against AIDS, the voluntary sector has been carrying a disproportionate burden in the war. For instance, at GMHC, over 76 percent of our budget is privately raised. We are falling farther and farther behind. We are losing the battle. Our case loads are increasing at a rate far outpacing our funding. While today GMHC has 2,800 clients, a year from now we will have 4,000 clients. That is a 42 percent increase in our case-load. We truly do not know what we are going to do to meet their needs.

Community based organizations are the Nation's front line troops in the war against AIDS. We have the credibility and the expertise to take messages on sexuality and drug use to people who are most at risk. However, we do not have the ammunition to win. We need large scale Federal assistance in the form of emergency relief. The recently introduced Care Act of 1990, S. 2240, must be supported. HIV positive individuals or families in community based organizations will be active and vigilant participants in local planning efforts to determine program priorities for funding and for people who haven't heard this today, that means that within one year, \$52 million for the city of New York, and \$57 million for the State of New York in the first year. The Public Health Service must recognize that it shares in the care responsibilities. This will bring all local efforts immediate financial assistance, but especially those in the hard hit cities. However, these important emergency relief funds will only be a bridge to more systemic relief that will be necessary to care for those effected.

Medicaid, AIDS and HIV amendments of 1990, H.R. 4080, is the type of comprehensive Federal approach to an early intervention program that must be supported and initiated as soon as possible.

With increasing helpful therapeutic developments, we are reaching many more individuals and families who want services. But, the sad fact is that while we have begun to see the results of our billion dollar investment in biomedical research, those therapies are out of the financial reach of the vast majority of those who need them. In addition, as AIDS education and outreach expands, and these programs must be expanded even more, individuals and families at risk are stepping forward to be tested. For those who are finding out they are positive, we begin the intake and referral process. In August and September of last year, GMHC's hotline was receiving 40 percent increases in calls. Most of those calls had

heard about the promising developments in AZT and they want to know where to find AZT, where to find the medical care.

There are few places we can send them. The frustrating and angering truth is that many of these callers do not have insurance and cannot afford a private doctor. Our local community health clinic was so overwhelmed by request for local help that they closed their waiting list for 2 months. They are caring for 1,400 HIV ill individuals with just two doctors. Our local self-help counseling group of HIV positive individuals has a counseling group made up of male drug users who want to get in the treatment but they are on the waiting list. Thousands of people in New York City are waiting list for residential drug treatment programs. They must wait weeks or months. For those who get ill and enter the hospital system, other barriers confront them.

GMHC's Ombudsman's office constantly investigates complaints of people with AIDS waiting days in emergency rooms for a hospital bed. Both in the public and voluntary systems, critically ill people can wait as long as 8 to 10 days. This last December, two of our clients died in the emergency room in a voluntary hospital while waiting for a bed. One waited eight days another waited 9 days. Once a patient is ready for discharge, they are very few subacute care or supportive housing programs available.

As we know, in New York City, as was mentioned before, is at the tip of the iceberg. According to the Department of Health here in New York City, 117,000 New Yorkers who are HIV positive have a T-cell count below 500. With the latest recommendations from the Secretary of Health, those 117,000 individuals should be receiving medical care in an early intervention program. The Secretary's recommendations mean that the number of people who should be receiving services has increased tenfold. We know we need the care for these individuals.

The HSA in New York City AIDS Task Force says we need the following for just these limited categories. But, in 1993, in just that year alone, it says we need, "Acute beds, 4,000; housing units, 2,600; health related facility beds, 600; skilled nursing facilities, 630; home care enrollment, 3,450; and" listen to this, "over 1 million physician visits." The local community based primary care clinic I just told you about, there is only four of them in the city. They can only handle 4,000 visits per year. This says in 1 year we need over 1 million physician visits. We aren't even close. The total cost for that over the 5 years is \$7.2 billion. Those costs do not include prevention, mental health, or substance abuse treatment.

The New York Times was not exaggerating when it says that New York is in danger of becoming a new Calcutta. So, in summary, as I sit before you today, just please remember that 50 more individuals, men, women and children, were diagnosed with AIDS in our city today. Four more people with AIDS came to GMHC for help today. We must not abandon these individuals and their families. We are not lacking in financial resources. We are lacking the political will to own this epidemic as our own. There are no others in this epidemic. To know that our health care system is at risk, if the behavior that puts us at risk is ignorance and complacency, we must have new and renewed national effort to provide leadership and resources to win in our war against AIDS. And we applaud

this hearing and hope that it will be a catalyst to a lot more work in getting the dollars to the programs that need it, and please don't forget the community based voluntary organizations.

[The prepared statement of Mr. Peterson may be found at end of hearing.]

Mr. SCHUMER. Thank you Mr. Peterson. I too hope it will be a catalyst.

Our next witness is Kathy Schrier, the Director of Education for District Council 37.

**STATEMENT OF KATHY SCHRIER, DIRECTOR OF EDUCATION,
AMERICAN FEDERATION OF STATE, COUNTY AND MUNICIPAL
EMPLOYEES, DISTRICT COUNCIL 37**

Ms. SCHRIER. Good afternoon Mr. Chairman. I will try to be brief and I will try to limit my remarks to things that haven't been said before because lots have been said and I could just get up here and says ditto, ditto, ditto, ditto. But, first of all, District Council 37, AFSCME, of the AFL-CIO represents 140,000 people who work for the city of New York, and I come here this afternoon not only on behalf of the 27,000 of our members who work in the public hospital system, but 140,000 members and their families and the 1.2 million members of the American Federation of State, County and Municipal Employees.

Your colleague, Congressman Waxman, said it all in his comments about his Medicaid amendments. He said we must make a start, and I hope we look at this as a start.

During the early years of the AIDS epidemic, we didn't know what was going on and our members, like Ms. King's members worked very hard in the public hospital system to deliver care when they did not know at that point if they could be infected by a disease that nobody knew anything about or how it was transmitted. We are very, very proud that our members worked with patients who had AIDS and have continued to work with patients that have AIDS but as mentioned before and I think it is worth repeating, to work you need not only the supplies to do your job, you need the staff, you need the support, you need the psychosocial support, and most important, you need to be able to work in dignity. To do that, you can't be told at 5 p.m., you have got to work a second shift and you have got to decide, I am exhausted, but if I go home, that patient isn't going to get fed, that room is not going to get cleaned, that patient is not going to get his or her medicine. What is the choice? Is that fair to make that choice to a worker? Is that fair to say to a worker should you continue to try and deliver service when you know you really don't have the ability, but if you don't do it nobody else is there.

We desperately need money for staffing. I am sorry your colleague Mr. Scheuer who had to leave because we found a solution. We have developed a number of paraprofessional titles, titles like medical/surgical technician, operating room technician, psychosocial health technician. Do you know what the dilemma is, we had to stop training for these positions. And the reason we had to stop the training is that there may be money to train the nurses aide to become a medical/surgical technician, to deliver the lower level of

nursing services to that patient, but then the problem is there is no money to backfill the vacated position. So, what are you doing? You are robbing from Peter to pay Paul. In addition, we have members and nursing career ladders which could resolve the nursing shortage. I am tired of hearing about a nursing shortage. We have the folks. They are on waiting lists to go into nursing schools. That is a tragedy in this day and age. The services are desperately needed in the health care system and these are not people that are going to be nurses who are going to leave, because they know what it is like to work in a health care system. They know what it is like to work at Bellevue Hospital or Kings County Hospital with patients that sometimes are difficult to work with.

We heard a lot today about people not getting the care that they need. Indeed, people need the care and maybe the worker who wouldn't clean the bathroom, maybe he or she didn't have the supplies, as Ms. King said, to do it properly and he or she wasn't able to go in there to clean that room in a way that would protect his or her own health. That is terribly, terribly important. There are patients in the public hospital system that need help and they need psychological help. A day does not go by that we don't get a phone call from a nurses aide or a social worker that says, "A patient who has AIDS cut himself with a knife and came after me with that knife and threatened me to stab me with that knife." That is not fair. Our members want to help these patients. These are patients that have psychological problems because they are victims of a society that wasn't supportive. But to do that, we need money. We need money for supplies and we need money for health care.

To do it, the Medicaid amendments as proposed will help. It is only a beginning. We need more money. That is all I have to say our members are here to service, we are here to give the service, but we need the support, we need more staff and we need the supplies to do our jobs. Thank you.

[The prepared statement of Ms. Schrier may be found at end of hearing.]

Mr. SCHUMER. Thank you Ms. Schrier. I can tell you from my experience that the people in your union in the public hospitals do a superb job. The only times I have been, thank goodness, in hospitals, whether it be good times like birth of children or bad times, death of grandparents, the workers have been amazing.

Our final witness who just arrived had been waiting a long time but was out of the room when we called the panel. Debra Fraser—I am not sure how to pronounce the last part of your name.

Mrs. FRASER-HOWZE. Howze.

Mr. SCHUMER. You probably get asked that question all the time.

Mrs. FRASER-HOWZE. All the time.

Mr. SCHUMER. Debra Fraser—were you originally Fraser or Howze?

Mrs. FRASER-HOWZE. I was originally Fraser, still Fraser.

Mr. SCHUMER. No, now you are Fraser-Howze, well you took on that hard part later on in life. She is the executive director of the Black Leadership Commission on AIDS and she will describe experience of clients in receiving care. Ms. Fraser-Howze, the one thing I would mention to you which I mentioned to the other witnesses is

that your entire statement will be read into the record. We are trying to wrap this up at a reasonable time so if you could.

Mrs. FRASER-HOWZE. I will be brief.

Mr. SCHUMER. Thank you.

**STATEMENT OF DEBRA FRASER-HOWZE, EXECUTIVE DIRECTOR,
BLACK LEADERSHIP COMMISSION ON AIDS**

Mrs. FRASER-HOWZE. First, I need to just tell you a little bit about the Commission. The Commission was formed in 1987 by 69 members of the Black Leadership for the city of New York, and our focus mainly is on technical assistance to community based organizations that service communities of color, mass education and some special projects that deal with very specific forms of education that are ethnically conducive as well as sensitive.

The vehicles we use may be a little different from vehicles that others have used and an example would be a program that we have developed that focuses on teaching beauticians in the Harlem community to be aides educators and allow them to teach women of color how to negotiate safe sex.

I am here to speak probably about the primary users of the HHC system in the city of New York which are the people that come from my community. As you know, we use HHC system as our primary health care, preventive health care services because there are no other services in the communities. We have long died from inadequacies and inequities in the health care system in New York City. AIDS is simply killing us faster. This is not new for us. But, as it goes along it focuses on the true inequities in this country for communities of color. We will not and just cannot deal with much more of this and I am here to tell you that from where I sit in my work and dealing on the community level, every day and being a child of the community and still living in the community. What you have is a community like a pressure cooker right now.

People are afraid to send their children out because they are afraid they will be shot by policemen, people are afraid to go into the hospital system because they think that they are not going to get any care at all. The hospital workers are themselves afraid because they don't have any money and they don't have the necessary services in order to give the kind of care that I know that they are committed to and want to give and this whole thing is just about to blow up and I say that very calmly because the people who come to us to speak to us are not calm, and we think that it is part of our social responsibility to try to keep them calm, but in the same event, we feel that it is part of our social responsibility to come here to people like you and to other policy makers and decision makers in this city and let you know that this thing is about to blow up.

There is fear and panic on both sides, from outside the hospital and inside the hospital. There is a major, major concern—when we talk about funding for education in communities of color and when I talk about communities of color, I want to preface this by saying that when I speak for my community, I don't speak against anyone else's community and I think that that is important for us to know, but when you look at the health care system and what is going on,

why do people in our community not know about a T-cell count, not even know what it is. Why don't we have beepers to tell us when to take our AZT? Why don't we have AZT? Why don't we have care givers that can administer the drug to us?

There is a real serious inequity problem going on here and it doesn't seem like it is going to get any better with the present state of finances in the city.

When we talk to people in our community and back to the education issue and you see a woman who is pregnant and give her some information about AIDS and she can tell you that the disease is going to be erased from her system once she delivers the baby through the birth canal, then you know that we have a real serious education problem going on here. I spoke at the last hearing in Washington because I was attending a meeting with the National Institute of Allergy and Infectious Diseases and there was a statement made on the floor by one of the doctors that the American Academy of Pediatrics Journal spoke about people who felt that they were high at risk and the fact that they should not breast feed. Well, I proceeded to ask the question and got more in depth information about it and was myself frightened and wondered why the Government had not proceeded to make this sort of information more widely available. The statement that was given back to me is, "Well, Mrs. Howze, it is in the American Journal of Pediatrics." Well, we don't read that journal on 125th Street and Lenox Avenue, and somebody is going to have to work with us and fund us to do the education that is necessary so that our women don't think that they are going to get rid of this disease when the baby comes out of their system.

The breast feeding issue is just one of the issues. The AZT issue is just one of the issues. The research issue is another issue. When we talked about the fact that blacks and hispanics make up such a minuscule amount of the people that are in these scientific protocols and you see that some of the drugs effect people that have a low level base health to begin with and you wonder, well, in general, since a lot of us are walking around with our systems already compromised and then we look at particularly the intravenous drug abuse population, how are these drugs going to effect us? I can't get a clear answer on that and somebody needs to give somebody some money so they can answer those questions for me because those are some very critical questions.

We have got to stop hospital workers and the doctors who mean so much to our community from walking out of places like Kings County Hospital emergency room with 35 people waiting for admission because they just can't take it any more. Now, either the Government comes forward to help those of us, all of us, black, GMHC, the hospitals, the unions that are out here trying to do something to help this issue or the communities, all of the communities will come to their own terms on this one. And, nobody, no civilized society sits back and watches their children die. Ninety percent of the children in this city effected with AIDS are black and hispanic and I leave that thought and I ask you to take that thought back to Congress as they are making decisions for dying people in a dying city. Thank you.

Mr. SCHUMER. Well thank you for a very powerful statement Mrs. Fraser-Howze. I have one question I would like to ask all of the panelists. I asked it of the first panel if you were here. The question is, Is our system on the brink of disaster? If we don't get help will it be in disaster, not just in trouble but in disaster within the next few years?

Mrs. FRASER-HOWZE. Absolutely.

Mr. SCHUMER. You say yes.

Mrs. FRASER-HOWZE. It is going to blow up and fall apart.

Mr. SCHUMER. Ms. Shrier.

Ms. SCHRIER. I think it is in disaster now. I mean, unnecessary deaths are happening every single day. It is in disaster now. It just isn't getting the publicity.

Mr. SCHUMER. Mr. Peterson.

Mr. PETERSON. Yes, our clients are in desperate need of services that aren't available so that is not the future that is now. Disaster is here.

Mr. SCHUMER. And Ms. King—

Mrs. FRASER-HOWZE. Mr. Schumer, Congressman Schumer, let me just ask one question.

Mr. SCHUMER. Go ahead.

Mrs. FRASER-HOWZE. I can't understand for the life of me, and maybe you can explain it to me, why the city of New York has not been declared a disaster area already, I mean with all of the statistics, look at this bar graph. You know, if they declared no other place in America a disaster at this point, New York City would have to be the place.

Mr. SCHUMER. I have thought about the same thing and one part of it is education. That is what this hearing is about in one way. You know, I used to feel when I ran for election and I thought I was losing, if I could get all of my constituents and put them in a football stadium and let them hear me 5 minutes and each of my opponents for 5 minutes, I would win. But the problem was I could never get them all in that football stadium. Well, we now face sort of the same thing. If we could get every Member of Congress just to sit and listen to the problems of New York for 20 minutes, 2 hours, whatever, they might understand.

The other part is that we have outdated ways of thinking of things. If there is a fire somewhere it is a natural disaster. But, if there is a human fire if you will, like AIDS, it is not considered disaster. I guess that comes from the 1800's when physical disasters were something Government was supposed to be involved in and, before the progressive era, Government wasn't supposed to be involved in people disasters. We are still 100 years behind the times. I give a speech, which I won't bore you with now, that our real problem now is people. Our real capital is people. If we want to be the leading power in this world, which most Americans do, it is no longer so much factories or farms that are the issues, it is human capital.

Mrs. FRASER-HOWZE. That's right.

Mr. SCHUMER. It is no longer building a B-2 bomber, it is making sure our people are healthy and educated and able to compete. So far that message is beginning to make progress, but it has a ways to go.

Mrs. FRASER-HOWZE. We are here to help you.

Mr. SCHUMER. This hearing has been a terrific educational experience for me and hopefully for other Members of Congress.

Ms. SCHRIER. I might like to make a suggestion. Perhaps these hearings should be held in places like Iowa and Kansas and we would be happy to come and testify out there and if they are not going to come to us, I speak on behalf of my membership, we will go to them and we will tell the story.

Mr. SCHUMER. That is a good point. And we try to have them around the country.

Thank you all very much, Ms. King, Mr. Peterson, Ms. Schrier, and Mrs. Fraser-Howze. Before I end, I want to thank again Cabrini Hospital for their work and hospitality. I want to thank the Budget Committee staff, Lynne Jolly Richardson and my staff, Clarke Camperand, and Tom Freedman. I want to thank our recorder. I always read the name of the recorder into the record because you are the forgotten soldiers. If you could tell me your name.

Mr. TANKOOS. Kenneth Tankoos.

Mr. SCHUMER. I would like to thank Kenneth Tankoos for doing the hard work he does to make sure that this keeps going. Thank you very much.

[Additional material submitted for the record follows.]

PREPARED STATEMENT OF ROBERT PETERSON

My name is Robert Peterson. I am a Policy Associate at the Gay Men's Health Crisis (GMHC), based in New York City. GMHC is the nation's oldest and largest community-based AIDS service, education and advocacy organization. Since our beginning in 1981, GHMC has directly served over 8500 people with AIDS or ARC. We have answered 300,000 calls for information on our Hotline. We have distributed 3,000,000 pieces of life saving information. We have trained thousands of health and mental health providers. We have prevented hundreds and hundreds of evictions and illegal job terminations. The vast majority of our work has been done by volunteers. We currently have 1700 volunteers giving over 10,000 hours of time every month- lawyers, social workers, therapists, cooks, office workers and nurses.

I speak to you today as a representative of dozens of community-based AIDS organizations in New York City providing psycho-social support, counseling, case management, food programs and legal and financial advocacy to the HIV-ill and their families, and prevention education and medical information to the general

public and targeted populations. I am here to tell you that while we fully believe in a private-public partnership, in the nation's war against AIDS, the voluntary sector has been carrying a disproportionate burden in that war. For instance, at GMHC, over 75% of our budget is privately raised. We are falling farther and farther behind. We are losing the battle. Our caseloads are increasing at a rate far outpacing our funding. While today GMHC has 2800 clients, a year from now we will have 4,000. That is a 42% increase in our caseload. We truly don't know how we are going to meet their needs.

Community-based organizations are the nation's frontline troops in the war against AIDS. We have the credibility and the expertise to take messages on sexuality and drug use to people most at risk. However, we do not have the ammunition to win. We need large scale federal assistance in the form of emergency relief. The recently introduced CARE Act of 1990 (S. 2240) must be supported. HIV-positive individuals, our families and community-based organizations will be active and vigilant participants in local planning efforts to determine program priorities for funding. The programs at HRSA need to be expanded immediately. The Public Health Service must recognize that it shares in the care responsibilities. This will bring to all local efforts immediate financial assistance, but especially those in the hardest hit cities.

However, these important emergency relief funds will only be a bridge to more systemic relief that will be necessary to care for those affected by HIV. Medicaid AIDS and HIV Amendments of 1990 (HR 4080) is the type of comprehensive federal approach to an early intervention program that must be supported and initiated as soon as possible.

With increasingly helpful therapeutic developments, we are reaching many more individuals and families who want services. But the sad fact is that while we have begun to see the results of our billion dollar investment in biomedical research, those therapies are out of the financial reach of the vast majority of those who need them. In addition, as AIDS education and outreach expands, and these programs must be expanded even more, individuals and families at risk are stepping forward to be tested. For those who are finding out they are positive, we begin the intake and referral process. In August and September of this last year, GMHC's Hotline was receiving 38% and 40% increases in calls. Most of those callers had heard about promising developments and wanted information on testing, AZT and where to find medical care. There are few places we can send them. The frustrating and angering truth is that many of these callers do not have insurance and can not afford a private doctor. Our local community health clinic was so overwhelmed by requests for help that they closed their waiting list for two months. They are caring for 1400 HIV-ill individuals with just two doctors. Our local self-help counseling group for

HIV-positive individuals has a counseling group made up of male drug users who want to get into treatment but are on waiting lists. Thousands of people in New York City are on waiting lists for residential drug treatment programs. They must wait weeks or months. For those who do get ill and enter the hospital system, other barriers confront them. GMHC's Ombudsman office constantly investigates complaints of people with AIDS waiting days in emergency rooms for a hospital bed. Both in the public and voluntary systems, critically ill people can wait as long as eight and ten days. This last December, two of our clients died in the emergency room in a voluntary hospital while waiting for a bed. One waited eight days; the other waited nine days. Once a patient is ready for discharge, there are very few sub-acute care, or supportive housing programs available.

And we know in New York City we are at the tip of the iceberg. According to the New York City Citizen's Commission on AIDS, up to 225,000 New Yorkers are HIV positive. According to the New York City Department of Health, 117,000 New Yorkers who are HIV positive have a T-cell count below 500. With the latest recommendations from the Secretary of Health, those 117,000 individuals should be receiving medical care in an early intervention program. The Secretary's recommendations mean that the number of people who should be receiving services has increased tenfold. We know what we need to care for these individuals. The HSA New York City Task Force on AIDS says we need the following, for just these limited

categories:

| <u>Category</u> | <u>1993 Need</u> |
|---------------------------------------|------------------|
| Acute Beds | 4,020 |
| Housing Units | 2,640 |
| Health Related Facility Beds | 590 |
| Skilled Nursing Facility Beds | 630 |
| Home Care Average Daily Enrollment | 3,450 |
| Physician Visits | 1,003,620 |

We are not prepared to cope with our HIV-ill in any of these categories. The cumulative costs for providing such services through 1993 were also projected:

| <u>Category</u> | <u>Costs</u> |
|---------------------------------------|-----------------|
| Acute Beds | \$4,409,000,000 |
| Housing Units | 233,000,000 |
| Health Related Facility Beds | 130,000,000 |
| Skilled Nursing Facility Beds | 235,000,000 |
| Home Care Average Daily Enrollment | 634,000,000 |
| Physician Visits | 496,000,000 |

These costs do not include education and prevention, mental health counseling or substance abuse treatment. Increased federal aid and

an early intervention Medicaid strategy could help us stave off disaster in New York City. The New York Times was not exaggerating when it said New York is in danger of becoming the new Calcutta. As I sit before you today, fifteen more individuals -- men, women and children -- were diagnosed with AIDS in our city. Four more people with AIDS came to GMHC for help today. We must not abandon these individuals and their families. We are not lacking the financial resources. We are lacking the political will to own this epidemic as our own. To know that there are no "others" in this epidemic. To know that our own health care system is at risk. That the behavior that puts us at risk is ignorance and complacency. We must have a new and renewed national effort to provide leadership and resources to win our war against AIDS.

PREPARED STATEMENT OF KATHERINE SCHRIER

MR. CHAIRMAN, MEMBERS OF THE COMMITTEE AND SUBCOMMITTEE, MY NAME IS KATHY SCHRIER. I AM THE DIRECTOR OF THE EDUCATION DEPARTMENT OF DISTRICT COUNCIL 37 AFSCME, AFL-CIO. I AM SPEAKING TODAY ON BEHALF OF STANLEY HILL, EXECUTIVE DIRECTOR OF DISTRICT COUNCIL 37 AND OUR 140,000 MEMBERS. WE ARE A UNION OF PUBLIC EMPLOYEES WHO WORK FOR THE CITY OF NEW YORK. MORE THAN 27,000 DC 37 MEMBERS WORK FOR THE NEW YORK CITY HEALTH AND HOSPITALS CORPORATION.

CONGRESSMAN HENRY WAXMAN'S COMMENTS WHEN HE INTRODUCED THIS LEGISLATION PINPOINT THE URGENCY AND NECESSITY FOR THE RESTRUCTURING OF FUNDING. HE CONCLUDED BY SAYING "WE MUST MAKE THE START". DISTRICT COUNCIL 37 AGREES THAT BETTER FUNDING FOR HIV - RELATED HEALTH CARE MUST BE AT THE TOP OF THE FEDERAL AGENDA.

THE AIDS CRISIS HAS TOUCHED THE LIVES OF DC 37'S MEMBERS IN MANY WAYS. IN THE EARLY YEARS, OUR MAIN CONCERN WAS GETTING THE FACTS. MEMBERS WERE ANXIOUS FOR INFORMATION ABOUT AIDS AND HOW THEY COULD PROTECT THEMSELVES ON THE JOB AND IN THEIR PRIVATE LIVES. MANY OF OUR MEMBERS WORK IN SETTINGS WHERE POTENTIAL EXPOSURE TO HIV AND OTHER BLOODBORNE VIRUSES IS A FACT OF LIFE. SOME OF OUR MEMBERS ARE NURSE AIDES WHO CARE FOR THE SICK AND DYING, HOUSEKEEPING AIDES WHO KEEP THE FACILITIES CLEAN, SOCIAL WORKERS WHO HELP PATIENTS DEAL WITH THE STRESS CAUSED BY ILLNESS, AND PHYSICAL THERAPISTS WHO HELP PATIENTS RETURN TO EVERY DAY LIFE.

WE AT DC 37 ARE VERY PROUD THAT OUR MEMBERS CONTINUED WORKING AND DID NOT SUCCUMB TO FEARS AND RUMORS CAUSED BY THE SUDDEN EMERGENCE OF THIS DISEASE. OUR UNION WORKED VERY HARD, AND CONTINUES TO WORK, TO MAKE SURE THAT OUR MEMBERS GET THE INFORMATION AND TRAINING, THEY NEED TO DEAL RATIONALLY WITH THE AIDS CRISIS.

WE HAVE LEARNED A LOT ABOUT AIDS AND ABOUT MAKING WORKPLACES SAFER FOR OUR MEMBERS AND THE PUBLIC THEY SERVE. BUT INFORMATION IS NOT ENOUGH. IT TAKES MONEY TO PROVIDE A SAFE WORK ENVIRONMENT, TO PROVIDE TRAINING, AND TO PROVIDE PROTECTIVE EQUIPMENT AND SUPPLIES THAT WORKERS NEED AND DESERVE. IT TAKES MONEY TO STAFF HOSPITALS ADEQUATELY - SO WORKERS CAN GIVE THEIR ALL TO CARE FOR PATIENTS IN ADDITION TO HAVING ENOUGH TIME TO FOLLOW SAFETY PRECAUTIONS CORRECTLY. AND IT TAKES MONEY TO PROVIDE SUPPORT PROGRAMS AND POLICIES FOR WORKERS WHO CONSTANTLY FACE LARGE NUMBERS OF YOUNG PATIENTS WHO ARE GRAVELY ILL AND DYING.

OUR HEALTH CARE SYSTEM IS IN CRISIS BECAUSE THE DOLLARS ARE NOT THERE TO PROVIDE BEDS AND SERVICES TO EVERY PERSON IN DESPERATE NEED OF CARE. THIS AFFECTS OUR MEMBERS WHO WORK IN HEALTH CARE FACILITIES BECAUSE THEY DEAL WITH OVERCROWDING AND SHORTAGES EVERY DAY ON THE JOB. IT AFFECTS ALL DC 37 MEMBERS, BECAUSE AS HEALTH CARE CONSUMERS, THEY TOO MUST FACE CROWDED EMERGENCY ROOMS AND LONG WAITS FOR BEDS WHEN THEY NEED MEDICAL CARE.

THE PROBLEMS AFFECTING HEALTH CARE DELIVERY IN NEW YORK CITY ARE COMPLEX AND DEEP-ROOTED. THEY DID NOT HAPPEN OVER NIGHT.

THEY DID NOT ARISE BECAUSE OF THE AIDS EPIDEMIC. NEW YORK CITY HAS ALWAYS BEEN THE PLACE WHERE THE IMMIGRANT, THE POOR AND THOSE LEFT OUT OF SOCIETY COULD GET THE SERVICES AND SUPPORT THEY NEED TO MAKE A NEW START. THESE GROUPS HAVE ALWAYS NEEDED THE FULL SPECTRUM OF HEALTH CARE SERVICES AND HHC HAS BEEN THERE TO PROVIDE THESE SERVICES. BUT THE SUDDEN INCREASE IN DEMAND FOR HEALTH CARE DUE TO THE AIDS EPIDEMIC HAS STRAINED A SYSTEM THAT WAS ALREADY STRUGGLING.

THERE ARE NOW 9,000 LIVING PERSONS IN NEW YORK CITY WHO HAVE CDC DEFINED AIDS.¹ MANY PEOPLE WITH AIDS REQUIRE HOSPITALIZATION AT SOME POINT. PATIENTS WITH AIDS SPENDS AN AVERAGE OF 35 OUT OF 365 DAYS PER YEAR IN A HOSPITAL BED.² THIRTY SEVEN PERCENT OF ALL BEDS USED BY HOSPITALIZED AIDS PATIENTS IN NYC IN 1988 WERE PROVIDED BY THE NYC HEALTH AND HOSPITALS CORPORATION.³ THERE IS NO REASON TO EXPECT THIS INFLUX OF AIDS PATIENTS INTO OUR CITY HOSPITALS WILL SLOW DOWN.

SEVENTY-NINE PERCENT OF THE PATIENTS TREATED FOR AIDS IN HHC FACILITIES HAVE THEIR EXPENSES PAID BY MEDICAID.⁴ IT HAS BEEN ESTIMATED THAT MEDICAID ONLY REIMBURSES EIGHTY PERCENT OF THE COSTS INCURRED BY HOSPITALS CARING FOR AIDS PATIENTS.⁵ WITH SO MANY AIDS PATIENTS WHO REQUIRE LONG HOSPITAL STAYS, THIS ADDS UP TO MILLIONS OF UNREIMBURSED DOLLARS EVERY YEAR. IN 1988, THE TEN PUBLIC HOSPITALS IN NEW YORK STATE WITH THE HIGHEST HIV/AIDS VOLUME LOST 530 MILLION DOLLARS⁶ WHICH OTHERWISE COULD HAVE BEEN PUT TOWARDS IMPROVING HEALTH CARE SERVICES AND WORKER SAFETY.

IT IS ESTIMATED THAT 1,200 TO 1,300 NEW ACUTE CARE BEDS WILL BE NEEDED IN NYC BY 1991 TO MEET THE NEEDS OF PATIENTS WITH HIV-RELATED DISEASES.⁷ ALTERNATIVE CARE FACILITIES AND HOUSING ARE BOTH SCARCE IN NEW YORK. BUT EVEN IF THEY BECAME MORE ABUNDANT, DEMANDS FOR HOSPITAL BEDS WILL INCREASE AS THE NUMBER OF PEOPLE WITH AIDS REQUIRING HOSPITALIZATION INCREASES.

THE WAXMAN-SCHUMER MEDICAID AIDS AND HIV AMENDMENTS WILL NOT SOLVE ALL OF THE PROBLEMS FACED BY NEW YORK CITY'S HEALTH CARE SYSTEM, BUT THEY ARE A START TOWARD EASING THE BURDEN CARRIED BY HOSPITALS SERVING LARGE NUMBERS OF LOW-INCOME HIV INFECTED PEOPLE.

IT MAKES SENSE TO GIVE STATES THE OPTION TO EXPAND ELIGIBILITY FOR MEDICAID, TO PROVIDE ACCESS TO EARLY INTERVENTION AND PRESCRIPTION DRUGS TO MEDICAID-ELIGIBLE, HIV-INFECTED PEOPLE. IF ADMINISTERED EARLY, MEDICATIONS CAN SLOW DOWN THE HEALTH DECLINE EXPERIENCED BY HIV POSITIVE INDIVIDUALS, ALLOW THEM TO CONTINUE FUNCTIONING IN THEIR DAILY LIVES AND POSTPONE THE NEED FOR HOSPITALIZATION.

THE BENEFITS OF THIS FOR THE PERSON WITH HIV INFECTION ARE OBVIOUS. SOCIETY WILL BENEFIT TOO, BECAUSE PROPHYLACTIC TREATMENT ON AN OUTPATIENT BASIS COSTS LESS THAN HOSPITALIZATION AND FREES UP SCARCE HOSPITAL BEDS.

IT MAKES SENSE TO IMPROVE MEDICAID PAYMENT TO HOSPITALS THAT SERVE A LARGE NUMBER OF AIDS PATIENTS. WHEN HOSPITALS LOSE TWENTY PERCENT OF WHAT IT COSTS THEM TO DELIVER CARE TO AIDS PATIENTS, THE LOSSES MUST BE MADE UP ELSEWHERE. PROGRAMS MAY HAVE TO BE CUT, CAPITAL IMPROVEMENT PROJECTS CANCELLED OR POSTPONED. WORN OUT EQUIPMENT CANNOT BE REPLACED. NEW WORKERS CANNOT BE HIRED. AS A RESULT ALL PATIENTS ARE CHEATED OF SERVICES AND CARE. AT DC 37 WE ARE ACUTELY AWARE OF WHAT UNDER-REIMBURSEMENT MEANS TO WORKERS IN HEALTH CARE FACILITIES. AT THE VERY TIME WHEN WORKERS NEED MORE RESOURCES TO HELP THEM DEAL WITH PSYCHOSOCIAL AND SAFETY PROBLEMS ARISING FROM THE AIDS CRISIS, THEY HAVE TO "MAKE DO" WITH LESS.

IT MAKES SENSE TO ALLOW STATES TO USE MEDICAID DOLLARS TO PAY FOR MEDICAID BENEFICIARIES CONTINUED COVERAGE UNDER COBRA. THIS MAY SAVE TAX DOLLARS IN THE LONG RUN AND DISTRIBUTE SOME OF THE BURDEN OF PAYING FOR AIDS-RELATED HEALTH CARE TO PRIVATE INSURANCE COMPANIES. A SIMILAR PROPOSAL WAS MADE BY THE MODELS OF CARE SUBGROUP OF THE HEALTH SERVICES AGENCY'S NEW YORK CITY AIDS TASK FORCE IN THEIR 1989 REPORT.⁸

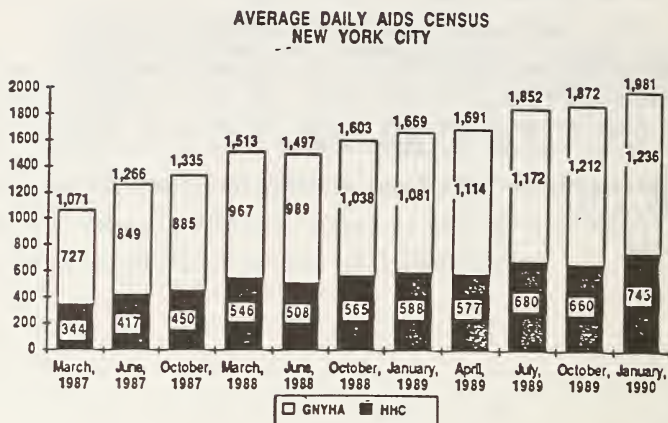
IT MAKES SENSE TO ALLOW STATES TO USE MEDICAID DOLLARS TO PROVIDE HOME AND COMMUNITY-BASED CARE TO CHILDREN WITH AIDS. OTHERWISE, THESE CHILDREN HAVE TO BE CONFINED TO HOSPITALS TO RECEIVE MEDICAID REIMBURSEMENT FOR TREATMENTS THEY MUST HAVE. CHILDREN WITH AIDS FACE VERY SHORT LIVES AND CONSTANT BOUTS OF TERRIBLE ILLNESS.

IT IS CRUEL TO FORCE THEM TO BE HOSPITALIZED ANYMORE THAN IS MEDICALLY NECESSARY SIMPLY BECAUSE WE CANNOT COME UP WITH A WAY TO FINANCE THEIR HOME HEALTH CARE. IT IS ALSO EXPENSIVE, AND AN UNNECESSARY USE OF ALREADY SCARCE ACUTE-CARE BEDS. IT MAKES MUCH MORE SENSE TO ALLOW THE USE OF MEDICAID DOLLARS FOR HEALTH CARE PROVIDED IN THE HOME OR COMMUNITY-BASED SETTINGS.

THE WAXMAN-SCHUMER PROPOSAL IS AN INTELLIGENT FIRST STEP TOWARDS DEALING WITH THE STRAIN THE AIDS CRISIS HAS PUT ON THE NEW YORK CITY HOSPITAL SYSTEM AND THE WORKERS AND PATIENTS IN THE SYSTEM. DC 37 SUPPORTS THIS PROPOSAL, BUT WE URGE OUR REPRESENTATIVES IN CONGRESS TO VIEW THIS LEGISLATION AS A BEGINNING, NOT AN END. AN ALL-OUT FEDERAL EFFORT IS CRUCIAL IF CITIES SUCH AS NEW YORK ARE GOING TO SURVIVE THE AIDS EPIDEMIC.

1. NEW YORK CITY DEPARTMENT OF HEALTH AIDS SURVEILLANCE UNIT:
AIDS SURVEILLANCE UPDATE, FEBRUARY 28, 1990, p.4.
2. PARRISH, R.L.: STATEMENT ON BEHALF OF THE NATIONAL ASSOCIATION
OF PUBLIC HOSPITALS BEFORE THE HOUSE ENERGY AND COMMERCE COMMITTEE,
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT, -UNITED STATES HOUSE
OF REPRESENTATIVES, FEBRUARY 27, 1990, p.7.
3. INTERAGENCY TASK FORCE ON AIDS: NEW YORK CITY STRATEGIC PLAN
FOR AIDS, MAY, 1988, p.E.2/1.
4. NEW YORK CITY HEALTH AND HOSPITALS CORPORATION: AIDS: THE CHALLENGE
FACING THE HHC SYSTEM, AUGUST 1, 1989, p. 16.
5. THORPE, K. E. : MEDICAID EXPENDITURES ON AIDS: FUTURE TRENDS
AND POLICY ISSUES. STATEMENT BEFORE THE COMMITTEE ON ENERGY
AND COMMERCE SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT
UNITED STATES HOUSE OF REPRESENTATIVES, FEBRUARY 27, 1990, p.2.
6. HOSPITAL ASSOCIATION OF NEW YORK STATE: THE IMPACT OF AIDS IN
NEW YORK STATE, JANUARY 15, 1990, p.20.
7. HEALTH SERVICES AGENCY: NEW YORK CITY AIDS TASK FORCE REPORT,
JULY 1989, p.22.
8. IBID, p. 63.

PREPARED STATEMENT OF KENNETH E. RASKE



Good morning, Congressman Schumer, members of the New York City Congressional delegation, ladies and gentleman. My name is Kenneth E. Raske. I am the President of the Greater New York Hospital Association (GNYHA) which represents 123 voluntary, non-profit hospitals and nursing homes in New York City and surrounding communities. On behalf of the Association, I would like to thank the Congressman for the opportunity to testify at this House Budget Committee hearing to discuss the hospital crisis in New York City and the impact the AIDS epidemic has had on the crisis.

The average daily census of AIDS patients tells much of the story of the AIDS epidemic. At a total of 1,981 as of this January, it illustrates how in this era of extremely high hospital occupancy, emergency room backups, critical shortages of nurses and other health care personnel, and serious underfinancing of New York's hospital system, the AIDS epidemic continues unabated and, consequently, consumes ever more of the system's limited resources.

Since March, 1987, GNYHA, in conjunction with the New York City Health and Hospitals Corporation (HHC), has been tracking the average daily census of AIDS patients. From the time of the first survey, the average daily census of AIDS patients has increased 85%. Patients diagnosed with AIDS currently occupy more than 8% of all medical/surgical beds Citywide. While AIDS is surely not the sole cause of today's hospital crisis, its presence highlights the weaknesses of our already fragile system.

New York State, and New York City in particular, has responded remarkably well to the wide range of demands created by the AIDS epidemic. For this, New York's Health Commissioner David Axelrod, M.D., deserves a great deal of credit. However, New York alone can no longer meet the increasing need for a complex network of services required by those with AIDS and HIV infection. The current level of resources available through State and local government is insufficient and health care facilities in New York City are severely strained. Relief from the Federal government is critically needed now.

That is why, on behalf of GNYHA's members, I wish to commend Congressman Schumer for recognizing the level of crisis facing hospitals in New York City and for having recently introduced a bill that would provide enhanced Medicaid reimbursement for those hospitals serving disproportionately large numbers of patients with AIDS. It is among the first proposals by the Congress in which the need for emergency aid to relieve some of the pressures created by the AIDS epidemic is recognized.

The New York State Department of Health (DOH) now predicts that by the year 1994, 5,000 hospital beds will be occupied by patients with AIDS with the consequent need for the following: 2,700 additional hospital beds, 500-800 additional skilled nursing facility (SNF) beds not currently utilized by AIDS patients, a total of 1,000-1,400 intermediate care facility (ICF) beds, a total of 15,000 home care slots and 15,000 additional health care workers. Meeting all of the care needs for the ever increasing number of patients will clearly require an enormous expansion of all types of patient care capacity.

The need for an expansion of services for those with HIV infection is further highlighted by two relatively recent announcements by the U.S. Centers for Disease Control regarding the effectiveness of early diagnosis and intervention in delaying the onset of AIDS in asymptomatic individuals. The first involves evidence indicating that preventive treatment with AZT can delay the onset of AIDS in HIV-positive individuals. In the second instance, clinical trials have demonstrated the effectiveness of aerosolized pentamidine in preventing pneumocystis carinii pneumonia in certain HIV-infected individuals.

However, while hospitals readily acknowledge the need for an expansion of services, and recognize that they are needed by their communities to assist in ways beyond traditional acute care, simply put, no expansion of capacity can be accomplished without a major reinvestment of both capital and operating dollars in hospitals. Congressman Schumer's AIDS initiative goes a long way toward recognizing both the increased costs associated with treating an ever increasing number of patients with AIDS as well as acknowledging that hospitals must first be restored to financial health if they are to successfully meet the challenges presented by the AIDS epidemic.

FISCAL SHORTFALLS IN CURRENT AIDS PAYMENT POLICIES

As early as 1986, the New York State Department of Health (DOH) acknowledged the difference in resource use between AIDS patients and other medical/surgical patients in calculating hospitals' inpatient per diem rates for Medicaid and other non-Medicare payers. Although at that time, the State's non-Medicare inpatient reimbursement system established average per diem rates regardless of patient diagnoses or treatment, these rates were case-mix adjusted by a certain weighting factor and applied to the number of AIDS patient days at each hospital. Consequently, hospitals received some revenue benefit during this time for their increased costs of treating AIDS patients. The weighting factor used for the rate adjustment was based on the findings of two studies on the costs of treating AIDS patients—one by DOH on the average cost of ancillary services and one by GNYHA on the average cost of routine services—both performed during the period between 1986 and 1987.

In 1987, New York State regulation (NYCRR Title 10 Part 405.40) authorized the establishment of designated AIDS Centers to provide integrated and comprehensive inpatient and outpatient services through a coordinated, case-managed approach to care. To qualify for designation as a Center, hospitals must meet program requirements specified in the regulations and receive approval by the New York State Department of Health. With such approval, hospitals are eligible to receive special per diem rates for AIDS patients treated in the Center. These rates are set based upon a negotiated arrangement between DOH and individual hospitals and have ranged between 30% and 40% more than the hospitals' average per diem rates based on 1987 allowable costs.

For the period 1988-1990, New York's inpatient reimbursement methodology for all non-Medicare payers set forth DRGs or case payments as a new payment method. However, this new system continued to use 1981 costs with certain adjustments as the basis of payment for the inpatient rates. New York's DRG classification system parallels the Federal Medicare DRG system with a number of modifications, most notably in the areas of neonatal care and AIDS. Hospitals approved as AIDS Centers are essentially exempt from the AIDS DRGs and continue to receive the negotiated per diem rates.

Therefore, in New York State two methods have evolved for the payment of AIDS inpatient care — special per diem rates for AIDS Centers and DRGs for other hospitals. Both methods are based on historical costs which are adjusted to some extent for the high resource intensity of AIDS patients. However, there are certain deficiencies inherent in using both this cost basis as well as the existing AIDS adjustments for both the per diem and DRG rates. Therefore, the primary question is whether these rates for AIDS patients have kept pace with the changing resource requirements and developing technology for this patient population.

Based upon the arguments outlined below, GNYHA concludes that New York's AIDS payment policies do not adequately reflect the high resource needs of patients with AIDS. A re-evaluation and adjustment of the AIDS rates needs to be undertaken to ensure that AIDS payments recognize today's costs of providing services to this important population. Federal funding needs to be secured in order both to meet the shortfall between what New York State pays and what it presently costs to treat these patients, as well as to facilitate an expansion of services.

The technical concerns GNYHA has with current payment policies include:

- o **Inadequate cost base:** The payment rates for AIDS cases, although adjusted for some additional staffing, medical/surgical supplies, therapies and ancillary services, are still fundamentally based on the same 1981 cost base as the rest of the non-Medicare inpatient rate system. This cost base fails to recognize some major areas of cost growth applicable to all patients as a result of compliance with Federal, State and local requirements. Examples of these new costs include medical waste handling and disposal, universal precautions, hospital malpractice insurance, discharge planning standards, the discharge review program, hazard communication standards and related requirements, water and sewer charges, emergency admissions and the increased cost of health care personnel generally.
- o **Per Diem AIDS Rates Need Updating:** As discussed in the article, "The Shaping of An AIDS Payment Policy in New York State" (see attached), since the development of the AIDS Center per diem rate structures, there have been changes in the resource use and available therapies for the treatment of AIDS patients, in addition to expanded requirements for the Centers without any attendant reimbursement. These new costs need to be recognized in the rates. Most significant is the recent specification of requirements for full-blown, specifically defined case management services. These services are very labor intensive and require significant increased efforts by clinicians, discharge planners, social workers and other hospital staff. A related problem is the long length of time it has taken between DOH approval of the hospital as a designated Center and the issuance of the enhanced per diem rates. Consequently, hospitals begin to incur the additional costs associated with designation yet do not receive the additional revenue until much later, in some cases up to one year.
- o **AIDS DRG Weights in Question:** The service intensity weights (SIWs) used to determine payment for the AIDS DRGs were reduced by 27% between 1988 and 1989. This reduction was based on a DOH study of a sample of hospitals treating AIDS patients in 1987. GNYHA opposed this reduction in AIDS payments because of deficiencies with respect to the study methodology. The SIWs need to be re-evaluated in a fair and consistent manner to ensure that there is appropriate recognition of the relative resource consumption of AIDS patients compared with those of other patients.

- o **ALC Rate Understates AIDS Costs:** The current payment system sets forth a separate and fixed rate for patients on alternate level of care (ALC) status regardless of patient illness, condition or resources used. This rate is applied to all patients, including those with AIDS. GNYHA asserts that this ALC rate is unreasonable for AIDS patients given the differences in services provided to AIDS patients as compared to those provided to average medical/surgical cases. AIDS patients continue to receive a relatively intense level of services while waiting for placement in either a residential health care facility or a home with home care services. The costs of these services need to be included in any ALC rate for AIDS patients.

The issues that GNYHA has identified with respect to New York's AIDS payment policies are consistent with nationally recognized concerns. A study by the National Association of Public Hospitals, published in the August 11, 1989, Journal of the American Medical Association, found that hospitals receive 80 cents of every \$1 spent on AIDS patients. Nationwide, hospitals lost, on average, \$136 per AIDS patient day compared to a \$26 average loss per patient day for other medical/surgical admissions. This evidence demonstrates the clear need for Federal relief.

In addition to the fiscal shortfalls created by New York's particular payment policies for AIDS, it is critical to note that the general reimbursement policies by both Federal as well as State government will inhibit, though indirectly, the ability of member hospitals to respond to the demands created by the AIDS epidemic. At the Federal level, the Bush Administration has proposed to cut capital reimbursement to urban hospitals by 25% (while proposing to cut capital payments to rural hospitals by 15%). Without adequate reimbursement for capital, hospitals in New York City will be unable to undertake facility renovations and expansions needed both to improve health service delivery overall as well as to meet the growing needs of the population with AIDS and HIV. Similarly, in his Executive Budget for fiscal year 1991, Governor Cuomo has proposed a reduction in Medicaid capital reimbursement that would produce roughly \$60 million in unreimbursed capital expenses in FY 1991 for GNYHA member hospitals alone.

Another proposal in the Governor's Budget is to further reduce payments for alternate level of care (ALC) patients — those who are medically ready for discharge but remain hospitalized because of the lack of availability of discharge options. Obviously, realization of this proposal would exacerbate an already inadequate ALC payment policy. GNYHA contends that AIDS cases consume more of such resources and the proposal to further reduce already inadequate ALC payments simply penalizes the hospitals for the lack of alternatives to hospital care—a circumstance over which they have no control.

What is perhaps most troubling is that these payment cuts are heaped upon a health care system already in financial ruin. A recent study, commissioned by the legislatively-created New York State Council on Health Care Financing, found that in 1988 hospitals Statewide experienced losses of \$1 billion. Bottom-line losses totalled \$584.7 million with most of those losses attributed to hospitals in New York City. Equally alarming is that by region of the State, hospitals in New York City account for 76% of the operating losses and 81.5% of the bottom line losses Statewide. The financial picture for 1989 suggests no improvement.

GNYHA MEMBERS' RESPONSE TO THE AIDS EPIDEMIC

Despite financial pressures, persistent overcrowding and shortages of staff, GNYHA member hospitals have consistently provided acute care inpatient services to approximately two-thirds of those persons with AIDS and HIV-related illnesses in New York City. Currently, GNYHA member hospitals are the only facilities in New York City officially designated by the New York State Department of Health as AIDS Centers. Additionally, many GNYHA member nursing homes are at various stages of developing long term care options for persons with AIDS (i.e., skilled nursing facility and health-related facility beds). Finally, our members are aggressively trying to increase the amount of outpatient care they can make available to persons with AIDS or HIV infection.

It is with this commitment to caring for those with AIDS and HIV infection, as demonstrated above, that I, on behalf of GNYHA, pledge full support for your AIDS Medicaid Initiative.

THE FEDERAL RESPONSE TO THE AIDS EPIDEMIC

Following is a quote from the final report of the New York City Mayoral Task Force on AIDS, released just one year ago.

The AIDS epidemic is a national emergency — not simply a New York City aberration. An estimated 1 to 1.5 million Americans are infected with the HIV virus. That this should have evoked a massive federal response is obvious. That the federal government has failed to provide aid and guidance to local municipalities such as New York, Newark, Los Angeles, Houston, San Francisco, and Miami is an unhappy fact of life... AIDS is a national emergency and the inadequate response to it a national failure.

I am heartened to sit before you this morning knowing that several initiatives for addressing the challenges created by the AIDS epidemic have recently been introduced by members of Congress. In addition to Congressman Schumer's AIDS Hospital Medicaid Initiative two additional, complementary Congressional proposals that would benefit those areas hardest hit by the AIDS epidemic have also been put forth.

The first, H.R. 4080, is the Medicaid AIDS and HIV Amendments of 1990 introduced by Congressmen Henry Waxman and James Scheuer. It would provide for: (1) optional Medicaid coverage of HIV-related services for certain HIV-positive individuals; (2) enhanced Medicaid reimbursement to hospitals treating a high volume of individuals with AIDS; (3) Federal Medicaid funding for payments of premiums for the continuation of health insurance coverage, as allowed for under amendments in the Consolidated Omnibus Budget Reconciliation Act (COBRA); and (4) optional State coverage of home and community-based services to children with AIDS. The Waxman/Scheuer proposal for enhanced Medicaid reimbursement for hospitals serving a disproportionate number of patients with AIDS utilizes the same eligibility criteria as Congressman Schumer's AIDS initiative. Its COBRA continuation provision would allow States to use Federal Medicaid funds to help certain HIV-infected individuals keep their employer-based insurance coverage. It should be noted that a similar proposal at the State level has been developed by New York State Governor Mario Cuomo.

Another initiative receiving significant attention at the Federal level is Senator Kennedy's Comprehensive AIDS Resource Emergency (CARE) Act of 1990 (S.2240). It proposes to: (1) provide emergency Federal relief for cities hardest hit by the AIDS epidemic, including financial support to hospitals and other health care providers serving a disproportionate share of low-income individuals with HIV disease; (2) develop comprehensive AIDS/HIV care networks to improve quality and availability of care, treatment and support services for individuals and families with AIDS and HIV disease; and (3) provide additional funds for HIV health services research. The CARE Act would provide \$250 million in direct aid to hospitals, nursing homes and other health care facilities in the 13 cities with 2,000 or more AIDS cases among their populations.

The Schumer AIDS Hospital Medicaid Initiative proposes a methodology similar to the Medicare program's disproportionate share adjustment (DSA) that provides for enhanced Medicare reimbursement for hospitals treating a disproportionate share of Medicare and Medicaid patients. Providing eligible hospitals with an additional payment of no less than 25% of current payment per Medicaid patient with AIDS will enable these hospitals to develop the needed services to meet the new and growing demand of the epidemic. The current fiscal constraints of hospitals in New York City inhibits them from establishing the complex network of services required by this patient population. Your proposal would go far in helping our members to meet this need.

The New York State Department of Health has expressed reservations about this proposal for enhanced reimbursement to certain high-volume AIDS providers. David Axelrod, M.D., New York State's Health Commissioner, contends that New York State has been in the forefront of enhancing reimbursement rates for AIDS patients and that requiring an additional 25% over and above the rates which are already paid would penalize New York State. GNYHA believes that given the realities of AIDS payments and the fiscal shortfalls noted earlier, coupled with growing demand for AIDS-related services, such enhanced reimbursement provided by the Federal government is absolutely critical now.

All of the Congressional initiatives described above are wholly consistent with and supportive of the recommendations made one year ago by the New York City Mayoral Task Force on AIDS. Each would go a long way toward addressing the health care crisis in New York City.

CONCLUSION

Tremendous deficits, emergency room overcrowding and a severe nursing shortage all contribute to New York City's current health care crisis. Compounding these ills is the AIDS epidemic which continues unabated. I have described for you today how, in the face of already-strained acute care capacity and growing demand for hospital services, the resources available to health care providers, by all levels of government, are being reduced.

Hospitals and nursing homes in New York City are struggling valiantly to meet the care needs of this City's large AIDS population but cannot continue to do so without some recognition by the Federal government of their efforts. Your proposal, and those of your colleagues described above, are precisely the shot in the arm GNYHA member institutions need both in order to remain viable as well as to expand the amount and range of HIV-related services they provide.

On behalf of GNYHA's members, I wish to thank you for your efforts to address the health care crisis in New York City with tangible solutions. We look forward to working closely with you and your staff to ensure that the AIDS Hospital Medicaid initiative becomes a legislative reality.

Thank you.

DRG'S

THE SHAPING OF AN AIDS PAYMENT POLICY IN NEW YORK STATE

by Dana Eisenmann Sherwin
Greater New York
Hospital Association

Hospital rate-setting in New York needs to keep pace with the growing and changing patterns of AIDS and the associated costs of services for this patient population. Without a timely response from the major third party payers to adjust the payment policy for AIDS patients as needed the capacity of the hospital system to provide an increasing service volume and an expanding list of treatment requirements will be severely limited. New York's experience with treating AIDS patients, both on an inpatient and outpatient basis, is relatively new—given the significant growth of the AIDS inpatient cases in the last few years. It is important, therefore, that as special reimbursement systems for AIDS patients are developed and evaluated that public policy makers consider the evolving course of treatment and affected populations in their financing decisions. This article points to several areas which need to be addressed in the shaping of an AIDS payment policy.

The Adequacy of the Rates

Hospitals that treat AIDS patients receive reimbursement generally on the basis of diagnosis related groups (DRGs) or special per diem rates for inpatient services. To qualify for the special per diem rates, hospitals must meet the requirements of and be approved by the New York State Department of Health (DOH) for AIDS Center designation. General program requirements for Center designation (as specified in NYCRR Title 10 Part 405.40) call for integrated and comprehensive services to AIDS patients with patient management through an interdisciplinary team approach.

Rate-setting for the special per diem payments is not done by regulation, but rather by negotiation between the individual hospital and DOH officials. Since the designation of the first AIDS Centers in 1987, the per diem rates authorized have ranged on average between 30% and 40% more than the hospital's average per diem rates based on 1987 allowable costs. To the extent that AIDS Center program costs are reflected adequately in the special rates and remain status quo, there will be lit-

tle concern with the financing of care to AIDS patients for these hospitals. However, if the hospitals' mix of AIDS patients changes, treatment regimens change and labor intensity requirements increase, hospitals may face great uncertainty about the financial viability of their AIDS programs. The rate-setting methodologies need to take these very real changes into consideration and provide appropriate adjustments to the inpatient per diem rates for AIDS patients.

There is evidence that the resource use of hospitalized AIDS patients is growing. Not only is the average daily census (ADC) of AIDS patients in hospitals in New York City steadily increasing, on average AIDS patients may tend to receive more, not less services today, as compared with AIDS patients a few years ago. Table 1 below illustrates the 57.9% growth in ADC of AIDS patients between 1987 and 1989. The average length of stay of adult AIDS cases has increased from 21.3 days in 1986 to 21.6 days in 1987, a 1.4% change.¹ The percentage of adult AIDS cases diagnosed that are intravenous drug users (IVDU) has increased from 43% in 1988 to 46% in 1989 (as of March 15, 1989).² This group, in general, poses extraordinary demands on hospital services because of complicating factors such as homelessness, social isolation and poverty.

Pharmaceutical intervention in the treatment of AIDS patients is expanding as drugs once available only under research programs are now being approved for use and applied to larger populations. However, many of these drugs, such as AZT and aerosolized pentamidine are very costly to hospitals and patients. Currently Medicaid is the only major third party payer that reimburses hospitals for the costs of these new and expensive drugs.

The increased role of parenteral nutrition therapy in the care of AIDS patients to prevent weight loss and malnutrition also results in increased costs. According to some clinical experts, up to 25% of AIDS patients will need this therapy at some point during

the course of their illness.³ Nutrition therapy is accompanied by frequent blood tests and the need for more nursing care. Additional supplies, including formulas and catheters, are needed. These new costs may not have been anticipated, but nonetheless reflect the changing resources required to provide quality care to AIDS patients.

As experience delivering care to AIDS patients grows, so does the delineation of what it means to provide case management services. In fact, guidelines for case management services to be provided under the AIDS Center program will soon be distributed by the New York State AIDS Institute. The true costs of case management services may not be recognized in the current rates because of these new and evolving requirements. Additionally, provider follow-ups on patient condition post discharge require staff time and are not always matched by continuing inpatient stays or outpatient visits to generate additional revenue. Consequently, it is uncertain whether the rates account for these added costs.

A new set of requirements for AIDS Centers and some other providers was recently proposed by the New York State Department of Health and calls for the provision of coordinated, case-managed services for infants, children, adolescents and pregnant women with HIV infection or who are antibody positive. These new requirements essentially extend and enrich service to an expanded population—women and children who test positive for the HIV virus but are asymptomatic. Needed services may include prevention, education, early identification and treatment, family centered care and support services and longitudinal case coordination with the emphasis on outpatient services.⁴ These services are labor intensive and costly and the payment for AIDS care needs to recognize the expenditures essential for meeting the objectives of this proposal policy.

Hospitals that are not designated as AIDS Centers are paid on the basis of AIDS DRGs. The inpatient reimbursement system for the three year term 1988-1990, which introduced payment on the basis of diagnosis related groups (DRGs), included fifteen DRGs to classify and pay for AIDS cases. In mid-1988, hospitals identified a problem with the DRG grouping logic for

AIDS cases—it was proven that confirmed AIDS cases were not being classified in the AIDS DRGs because certain diagnoses were not appropriately considered by the grouping program. This problem was apparently resolved by a change in the DRGs for 1989. Additionally, based on 1987 experience with AIDS, the number of AIDS DRGs was changed from 15 to 12 and the associated service intensity weights for AIDS cases were reduced by 27% for payments in 1989.

the costs of treatment and patient management requirements.

The Appropriateness of the AIDS DRGs

Because of the problem with the AIDS DRG grouping logic noted earlier, there may need to be a re-examination of the appropriateness of the AIDS DRG classifications as a method of paying for AIDS cases. As manifestations of HIV and HIV related illnesses change through time, a DRG

"True costs of case management services may not be recognized in the current rates."

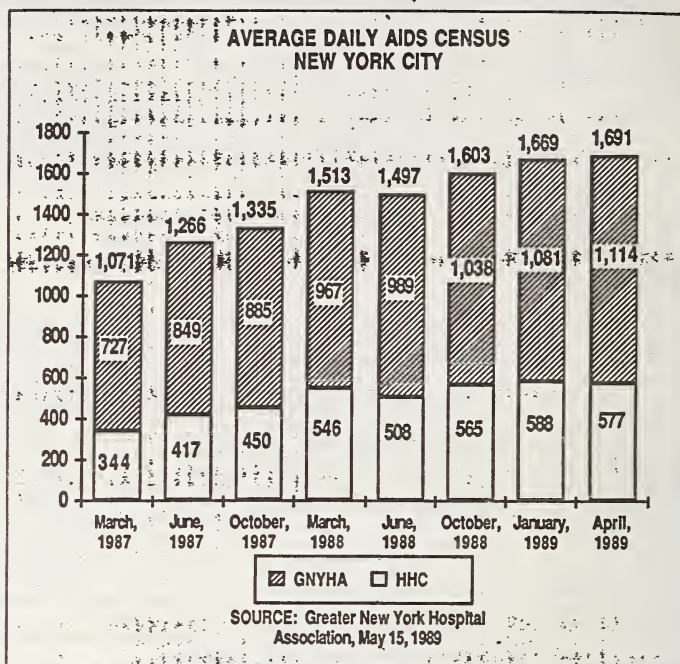
This reduction was due to several factors, according to DOH, including a change in the sample of AIDS cases reviewed, a change in the grouping logic and a change in the nursing intensity weights. However, it is uncertain whether the sample of cases and the nursing weighting methodology used were valid measures of the change in relative resource use by AIDS patients compared with other patients. Because of the growth in AIDS cases, changes in AIDS case mix and the evolution in service delivery and treatment technologies, the AIDS DRG payment rates need to be reevaluated at least annually to ensure adequacy of reimbursement for AIDS cases.

The AIDS Centers are paid for outpatient services provided to Medicaid patients according to a pricing schedule based on type of visit. These prices are fixed and applicable to all Centers regardless of actual costs of services rendered. Because these prices went into effect in 1988 and most of the Centers received designation in 1988 and 1989, it is too early to evaluate the adequacy of the pricing scheme. However, these rates are higher than the Medicaid clinic rate, which has been capped at \$60 per visit since 1981. It is important to note, however, that hospitals that are not Centers are reimbursed for outpatient care to AIDS patients at the capped clinic rate. If outpatient services are to be expanded to the AIDS patient population regardless of Center designation, then the outpatient rate structure needs to recognize

system for AIDS may not be flexible enough to accommodate such changes and therefore may not be able to appropriately identify AIDS cases and predict average resource use of AIDS cases. Additionally, some patients with AIDS may be admitted principally because of a condition not specifically related to AIDS but which occurs because of their general weakened condition. Such cases are likely to not be classified into the AIDS DRG, even though the patient requires a level of care similar to that provided to other AIDS patients. Failure to classify these cases into an AIDS DRG results in underpayments to hospitals for the care of patients with HIV illnesses and related conditions.

The Rationality of the ALC Policy for AIDS

The current reimbursement system for the non-Medicare payers pays for alternate level of care (ALC) at a specified and fixed rate based on 1987 group average operating costs of hospital based residential health care facilities trended to each rate year. This policy is applicable to all patients regardless of age, illness, condition or resources used. However, there is concern about the reasonableness of applying this policy to AIDS patients, focusing on the question of whether there are fundamental differences in ALC services provided to AIDS patients as compared with general medical/surgical cases. Do AIDS patients continue to consume acute care resources including intensive staff time as they



await placement in a residential health care facility or a home with home care services? Are social work services, drug therapies, counselling services and case coordination mitigated once it is known that an AIDS patient is ready for discharge? Probably not. The ALC rate for AIDS patients needs to adequately compensate hospitals for the continued labor intensive services provided to AIDS patients during ALC status.

New York State's policy with respect to the financing of care provided to AIDS patients needs to recognize the changing resource requirements and the special needs of AIDS patients.

Payment policies should ensure that the costs of needed care are covered. Only in this way can New York's health care community provide the volume and array of service critically required by the AIDS population. ■

NOTES:

1. "Assuring Care for New York City's AIDS Population," report of the Mayor's Task Force on AIDS, March 1989.
2. AIDS Surveillance Update, March 29, 1989, New York City Department of Health, AIDS Surveillance Unit.
3. "Nutrition Therapy, New to AIDS Patients, Raises Ethical Issues," *New York Times*, March 21, 1989.
4. *New York State Register*, April 26, 1988, Proposed Rule Making on Pediatric and Maternal HIV Services.

Dana Eisenmann Sherwin

Ms. Sherwin is the Vice President, Health Economics and Finance of Greater New York Hospital Association, a metropolitan hospital association representing 110 not-for-profit hospitals and long term care facilities in New York City and surrounding communities. GNYHA represents its members through advocacy, policy analysis, research and educational services. Ms. Eisenmann holds a Master of Health Services Administration degree from The University of Michigan and a Bachelor of Science degree from Cornell University.

PREPARED STATEMENT OF ALAN H. CHANNING

Mr. Chairman, Members of the Committee, I am Alan Channing, Executive Director of Bellevue Hospital, one of the member institutions of the New York City Health and Hospitals Corporation (HHC). I am here today to discuss the impact of AIDS on HHC and to offer support for your legislative initiative to assist hospitals treating a disproportionate share of AIDS patients. As you know, public hospitals are major providers of care to AIDS patients, and we welcome any assistance for our beleaguered hospitals in dealing with the extraordinary demands placed on them by this health crisis.

Our hospitals continue to operate in an environment of unprecedented overcrowding. We are struggling against staggering odds simply to meet the most urgent of the City's rapidly escalating health care demands. The AIDS epidemic has grown relentlessly through the eighties along with epidemics of drug abuse and mental illness. The incidence of poverty, homelessness and violence has also grown dramatically. And more and more New Yorkers lack medical insurance -- now one out of five, most of them women and children.

The exploding demand has placed increased pressure on acute care hospitals and this has been compounded by the scarcity of primary and preventive care resources that might prevent medical emergencies and hospitalizations, and the shortage of appropriate discharge options such as long term care and other after care. Neither is financed adequately by the reimbursement system. Patients are staying in the hospital

longer, suggesting that they are more seriously ill, have no place to which they may be discharged, or both. Finally, on top all this, we have a serious shortage of critical health care personnel. As a result, both HHC and voluntary hospitals are now facing a medical gridlock which, if unabated, will threaten both access to and quality of care for all New Yorkers.

The impact of AIDS has been especially dramatic at HHC. We care for more people with AIDS than any other single provider in New York City and the country. Our average daily AIDS inpatient census is now 625 -- triple the census in 1985. With only 16 percent of the medical-surgical bed capacity in New York City, we are now providing over one-third of the City's inpatient care for persons with AIDS. Bellevue Hospital cares for more patients with AIDS than any single hospital in the country. We have had what is approaching a decade's worth of unprecedented experience and in the process have had to grapple with unique and challenging realities. Let me mention a few of these.

First, AIDS care involves a complex interaction of medical, social and psychological needs that demands an interdisciplinary approach and case management services in both inpatient and outpatient settings to ensure continuity of care. Reimbursement for these services has been historically non-existent or inadequate. Without appropriate reimbursement,

the already disproportionate burden on the public hospitals as the providers of last resort will increase.

Second, the interrelationship between AIDS and IV drug use has brought attention to the larger implications for financing drug treatment programs generally.

Third, AIDS has helped bring to light the inadequacies of the post-hospital care system. Since the level of care required by AIDS patients often varies over time if we are to maintain continuity of care, there must be appropriate financial incentives for the development and the provision of a wide range of services including chronic care services, home care, supportive housing and ambulatory care. In New York City, long stay cases - those with total patient days over 30 days - play an important role in hospital use by AIDS patients. If every AIDS patient could be discharged to appropriate long term care services or supportive housing after 30 days, some 350 acute care beds would be freed up.

Finally, homelessness is a particularly difficult problem for persons with AIDS. This must be addressed within the larger context of housing needs without necessarily being based on a medical model.

HHC has had to deal with each and every one of these issues. We have eleven acute care hospitals with 7,800 beds, five long term care facilities with nearly 2500 beds, five Neighborhood Family Care Centers, twelve smaller community

based primary care centers, and six certified home health care agencies. We also operate the Emergency Medical Service which has almost one million ambulance runs a year.

Our mission is to provide high quality medical care to all, regardless of race, sex, diagnosis or ability to pay. Our patient population is predominately from low-income and minority communities. HHC is a major provider of health services in New York City, providing half of all ambulatory and emergency room visits, half of all inpatient psychiatric services and a third of all inpatient drug detoxification services as well as about 10-15 percent of outpatient drug treatment slots in the City.

Public hospitals like HHC have traditionally been the health care providers most affected by the social and economic changes in our society. Most recently, we have been at the forefront in confronting the AIDS crisis. Our AIDS patients are sicker and poorer than AIDS patients seen in non-HHC hospitals. Eighty-five percent of our AIDS patients are emergency admissions. A full 75 percent contracted the virus as a result of intravenous drug use -- either through direct IV use, sexual contact with an IV user, or being born to an IV drug abuser. By contrast, IV drug abusers make up less than 10 percent of the AIDS population in San Francisco and just over one-third in the City of New York. One quarter of our AIDS patients are women; nationally less than 10 percent are.

Almost 90 percent of our AIDS cases are minority compared with 40 percent nationally. In terms of payor mix, 80 percent of our patients are Medicaid, almost twice as much as non-HHC hospitals.

Projections for the near future are grim. Between June, 1989 and the end of 1993 cumulative AIDS cases Citywide will triple; new cases will double. To handle this growing caseload, we will need 3,250 more acute care beds citywide, the equivalent of six or seven new hospitals of 500 beds each. Without these new beds, by 1993, 39 percent of HHC's medical surgical beds, and 17 percent of the medical surgical beds in other hospitals in the City, will be occupied by people with AIDS/HIV-illness.

Other services will also be needed in addition to acute care. Over the next five years approximately 200,000 people will need outpatient treatment, nearly 1 million visits per year by 1993. With recent treatment advances, these services will be critical to the success of our fight against this disease. A full 25 percent of the City's AIDS/HIV-ill being discharged from hospitals will need housing, including supportive residences. Others will need rent assistance to enable them to remain in their homes. This will mean 1,590 supported housing units next year, with nearly 1,000 more beds by 1993. Provision of these services is an essential part of the continuum of treatment for the AIDS/HIV-ill, and will

result in fewer hospitalizations and nursing home admissions or earlier hospital discharge. We will also need additional alternate care resources, over 1,000 health related and skilled nursing beds and home care for over 10,000 individuals, over twice the number this year.

Future projections will also show a shift in new cases toward the IV drug using population. This will have special implications for New York City where the at risk population is large - about 200,000, 60% of whom are estimated to be HIV positive. Increasing numbers of women and children will be affected, as will low income and minority communities.

How has HHC responded to the AIDS crisis? Let me briefly describe some of the programs and initiatives we have developed in the areas of acute, ambulatory and long term care.

Acute Care

As noted earlier, with only 16 percent of the medical and surgical beds in the City, HHC hospitals provide medical services to 35 percent of those infected with the AIDS virus in New York City. We have 37 interdisciplinary inpatient AIDS teams comprised of physicians, nurses, nurse clinicians, physician assistants, social workers, and nutritionists, to provide the enhanced services required by this patient population. If the public sector continues to care for this disproportionate share, our ability to provide care for our traditional patient population will be seriously compromised.

In the current fiscal year HHC will spend more than \$300 million on services for people with AIDS - including direct medical care, supplies, social services, health education, and salaries - 43 percent more than in Fiscal 1989 and an increase of more than \$286 million since Fiscal 1985.

Ambulatory Care

We estimate that for every inpatient with AIDS, we are providing care for 5 outpatients. HHC will provide services to 8,000 patients this fiscal year at a cost of \$35.8 million. This is an increase of 4,800 outpatients since Fiscal 1989. HHC also expects to provide AZT therapy to 2,500 individuals compared with 1,249 at the end of Fiscal 1989 and 798 at the end of Fiscal 1988. We operate three community based primary care assessment centers - the only ones in the City - which provide the full range of medical and psychosocial support to persons at risk and those with HIV illness. All centers have long waiting lists. We also provide counseling and testing at 17 sites to women of child bearing age. Four HHC teams at three sites provide PCP prophylaxis and management of individuals who are severely immuno-depressed. We are in the process of opening twelve additional on and off-site comprehensive interdisciplinary outpatient programs for HIV at risk or ill populations. Finally, we operate the only pediatric AIDS day care center.

Long Term Care

We estimate that 8 percent of our inpatients remain in acute care facilities because of inadequate housing. They simply need a clean place to live where the necessary support services can be provided. No current institutional model meets the needs of these patients. HHC's long term care beds make up about 5 percent of the City's capacity for this level of care, yet we were the first and are currently among the few long term care providers in the City caring for AIDS patients. We have 86 medical long term care and 28 psychiatric long term care beds for AIDS patients.

The public sector simply cannot continue to bear such a disproportionate share of the responsibility of caring for the AIDS/HIV-ill. The Federal government must ensure that it is an equal partner with the States and localities in providing for the health and service needs of this population. Most importantly, the Federal government must extend Federal Medicaid coverage to single individuals who are HIV-ill. Current Federal eligibility for the HIV-ill is limited to low-income persons who have children or are receiving SSI, which is primarily available only to those with full blown AIDS. With the advent of effective treatment for the HIV-ill, states and localities will be left to absorb the increasing treatment costs without federal participation.

We need the voluntary sector to expand the amount of care

they provide to persons with AIDS -- in both the acute and long term care settings. The federal government must, therefore, ensure reimbursement for the full cost of AIDS patient care in order to prevent any financial disincentive for caring for AIDS patients which could ultimately result in the "dumping" of AIDS patients on the public providers. Moreover, the Medicaid inpatient adjustment rate for patients with AIDS and for HIV positive individuals should be increased for hospitals serving a disproportionate number of AIDS patients.

There is no doubt that our battle against AIDS must be accompanied by a significant expansion of drug treatment slots. Medicare and Medicaid reimbursement must pay for the additional costs of treating a drug user with AIDS - whether it is in or out of the hospital setting.

Overall, about 15 percent of our hospitalized AIDS patients are homeless and do not need long-term health care services. They simply need a clean place to live where the necessary support services can be provided. Many are ambulatory and could even go to an outpatient clinic if they only had an apartment. The housing needs of these AIDS patients are not met by any current institutional models. The Federal government must provide funding to major urban areas to construct and rehabilitate housing units for people with AIDS and to subsidize rents in existing apartments.

The need for appropriate ambulatory care services, long

term beds, home care, and supportive housing is critical. AIDS patients fluctuate frequently between levels of care required. Yet our health care system and its payment mechanisms do not facilitate such movement back and forth across the various levels of care. Thus, increasing numbers of AIDS patients remain in hospital beds weeks and sometimes even months, much of the time not in need of acute hospitalization. AIDS patients with a history of IV drug abuse are more likely than other AIDS patients to face these post acute care placement problems.

The Federal government must address the adequate reimbursement for the delivery of ambulatory care for AIDS patients. This will help assure that there are ambulatory care services for the increasing numbers of persons with AIDS. Our ambulatory settings need to be reimbursed adequately for all costs of caring for a person with AIDS including drug therapy and mental health needs. Federal Medicaid eligibility for outpatient services should be extended to individuals with HIV related illnesses and disproportionate share hospitals should receive a rate adjustment. The federal government should also take a more active role in providing incentives to states to develop outpatient and community-based treatment programs.

Finally, I would like to call your attention to the need for additional health and related service providers in areas

hard hit by the epidemic. Services will never reach those in need if critical providers are not available. Congress should revitalize and redirect the National Health Service Corps. The impact of HIV infection should be reflected in the designation of underserved areas and the types of providers should be expanded to include a broader range of health care professionals.

In closing, Mr. Chairman, I believe we have all come to recognize that the problems posed for our health care system by AIDS/HIV-illness are inseparable from the problems posed by the medically disenfranchised. The public hospitals in this country have been at the vanguard of addressing these problems and highlighting the need for major reform of the overall health care system. We will continue to press for public policy that assures access to the full range of health care from primary care to long term care, equitable participation by all levels of government, and explicit recognition of the additional stresses placed on disproportionate share providers. Thank you.

PREPARED STATEMENT OF WOODROW A. MYERS, JR., M.D.**Impact of AIDS and HIV on New York City**

Nowhere else in the nation are the challenges of the new epidemic of AIDS making themselves felt as strongly as in New York City. The cumulative number of AIDS cases here — more than 25,000 as of March 1990 — exceeds the combined total reported from the next four U.S. cities: Los Angeles, San Francisco, Houston, and Washington D.C.

More than 15,200 New Yorkers have died from AIDS, now the leading cause of death among New York men aged 30–44 years; women aged 25–39 years, and children aged 1–4 years. Almost 4,000 women and 600 children have been diagnosed with AIDS in New York City.

We estimate that between 125,000 and 235,000 New Yorkers are infected with HIV. This includes up to 60% of the city's estimated 200,000 IV drug users; 50,000 men who have sex with men; and thousands of others, primarily women, infected through heterosexual contact with an IV drug user. About 1,800 infants are born to HIV-infected mothers in New York City each year; approximately one-third of these children will develop HIV illness by 15 months.

It is now clearly recognized that the burden of the epidemic on our hospitals and in our communities extends far beyond the number of CDC-defined AIDS cases. HIV-infected people suffer many clinical and functional problems prior to being diagnosed with AIDS, and this full spectrum of HIV illness requires a wide range of medical and support services. For three years, we have worked hard to shift the focus of service delivery planning away from CDC-defined AIDS to the broader, more appropriate concept of HIV illness.

Epidemics of syphilis and TB parallel the HIV epidemic in New York City, and there is now a strong basis for believing that many new cases of TB are a result of HIV infection. We continue to study whether syphilis and other STDs facilitate the spread of HIV through genital lesions. Almost 8,000 cases of syphilis and 2,600 cases of TB were reported in the City in 1989.

By 1993, we project that 60,000 people will have developed AIDS in New York City, more than double the present number; 48,000 people will have died. More than 10,000 new cases will be diagnosed in 1993 alone, almost double 1989's figure. If we counted the addicts who are sick and dying from tuberculosis and other diseases related to HIV infection but not officially classified as AIDS, projections would be very much higher. CDC now reports that the epidemic is leveling-off in some respects. We note, however, that even if the rate of growth for new AIDS cases has slowed, we will not see much relief here in the near future. Every year, New York City will continue to see a very large number of new HIV disease cases requiring clinical monitoring and care and other services.

Two trends in the epidemic will have a great impact during the next five years. The first is the epidemic's changing profile, marked by the increasing role of substance abusers. In 1989, IV drug users accounted for 46% of new AIDS cases, in contrast to the early days of the epidemic when almost three-quarters of the reported cases of AIDS in New York City were among men who have sex with men.

Increasingly, cocaine and crack fuel the spread of HIV infection among drug users and their sex partners. Those who inject cocaine do so more often than heroin

users, and are thus at greater risk of infection through shared needles. The intense crack epidemic, with its fierce addiction and sex-for-drugs transactions, is related to increases in heterosexually-transmitted HIV infection, as well as to explosive recent increases in other sexually transmitted diseases. This occurs in areas of New York where genital ulcer disease is common and there is a high prevalence of HIV infection. We are conducting a study at a sexually transmitted disease clinic in the South Bronx. Among the crack users there who deny IV drug use, male to male sexual activity or sexual contact with an IVDU, 18% have tested HIV positive.

HIV-related sickness and death in drug users, their sex partners, and children are battering the City's poor and minority residents. Blacks and hispanics, disproportionately represented among the poor and therefore among drug users, comprise over 60% of AIDS cases reported among all New Yorkers, 84% of cases reported among women, and 90% of cases reported among children.

The second development which will have a great impact is the growing demand for clinical, preventive, and social services as a result of the broadening treatment horizon. More effective therapies are rapidly becoming available for treating and preventing opportunistic infections. The CDC has recommended that all HIV-infected persons be medically evaluated every six months; recent studies have shown that the drug AZT slows the progress of HIV illness in asymptomatic people and those with early symptoms, making tens of thousands of New Yorkers candidates for treatment.

DOH estimates that possibly half of all HIV-infected New Yorkers already have T4-cell counts of below 500. This is an indication that their immune systems are significantly compromised. The estimate is important in light of current treatment standards for early intervention that can prolong life. Our analysis suggests that between 37,000 and 70,000 persons should be assessed for a preventive treatment regimen of low-dose AZT, and that an additional 25,000 to 47,000 should be receiving other medical treatments to prevent PCP, in addition to AZT. The benefit to the thousands of HIV-infected New Yorkers could be great; but meeting this treatment obligation would add a significant new burden to an already stressed treatment system.

Impact of AIDS and HIV on Hospitals in New York City

In 1989, the New York City AIDS Task Force, comprised of leaders from the public and private sectors, concluded that "the full spectrum of services needed by the HIV-infected should be provided throughout the entire course of their HIV illness, from the earliest asymptomatic stage forward." The Task Force developed projections for two services which have a direct bearing on hospitals: acute care beds and ambulatory care physician visits.

(1) By the end of 1990, 3,020 acute care beds will be needed across municipal and voluntary hospitals. Three years later, more than 4,000 such beds will be required to meet the needs of persons with AIDS or serious HIV-illness. Currently, 1,900 hospital beds in New York City are occupied each day by HIV-ill patients. It is important to note that the projection for acute care assumes that an adequate supply of alternate services, such as supportive housing, home health care, and long-term care facilities, will be developed during the same period.

(2) The Task Force also projects that by the end of 1990, hospitals will have to provide more than 950,000 out-patient visits if the system is to keep pace with the growing need for HIV primary care. By the end of 1993, the projected number exceeds one million visits. At present, the supply of primary care services for HIV-ill persons in New York City falls far short of meeting the need for medical assessment, periodic monitoring of immune status and symptoms, and treatment of HIV-ill persons. Compared to other regions, much of the primary care in New York City is delivered in hospital-based settings. The AIDS epidemic has hit out-patient clinics hard. Waits for an intake visit for someone who has received an HIV-positive test result is three months in some hospitals. There is a need to shift some of this ambulatory care burden to newly-developed or better-supported primary care services at the community level.

In addition to the funding required to expand existing primary care, hospitals are experiencing equally damaging manpower shortages. Hospitals cannot attract and hire enough physicians, physician assistants, nurses, and social workers to provide HIV-related care.

NYCDOH Role in Early Intervention

Earlier in the epidemic, DOH program activities centered almost entirely on what is usually called "primary prevention": education and counseling oriented to controlling the spread of HIV. Recently, with growing evidence that effective prophylactic treatments can prolong life, DOH has begun to provide more information and counseling to facilitate early identification of seropositive people

and referral for treatment and support services. The availability and quality of assistance and medical care for those infected can also influence risk behavior. Persons who are given hope and support will act more responsibly toward themselves and others. The HIV-positive addict given drug treatment and health care opportunities is more likely to abandon needle-sharing and other risk behaviors.

In earlier years DOH did not actively recommend and promote HIV antibody testing. We now urge all who may be at risk to "know their antibody status" so that they can avail themselves of necessary primary care and prophylactic treatment that can make their lives longer. Through the Department's Anonymous Counseling and Testing Sites (ACTS), and in its STD and TB clinics, almost 3,000 people receive HIV counseling each month; approximately 400 learn that they are HIV-positive. This means that DOH alone identifies nearly 5,000 new HIV-positives each year, many of whom have no primary care physician and lack the resources to obtain adequate medical care. Our counselors continually struggle to place a growing proportion of their HIV-positive clients in primary care — in municipal or voluntary institutions.

The Department also encourages medical institutions that provide HIV care to establish competent HIV counseling/testing services. We do this very concretely by training counselors for other institutions, by outposting our own trained employees in such institutions, and by providing contract funds for HIV counseling and testing services within medical institutions. DOH provides free laboratory services to

physicians and institutions who are conducting HIV testing; more than 6,000 physicians have used this service to support the hospital-based and office-based clinical care they provide.

Recommendations to Congress

One important lesson we have learned in responding to the epidemic is that the health and social services necessary to provide a continuum of care for HIV ill persons are deeply interrelated. For example, increasing availability of housing resources will help ensure that nursing homes and other health-related facilities are not inappropriately forced to house HIV ill individuals who do not need that level of care; development of housing and long-term care resources will also decrease the need for extended acute care hospital stays. Funding drug treatment programs serves a dual role: 1) as a prevention initiative and 2) as a means to reduce drug related demands on hospital emergency room and out-patient ambulatory care services.

- 1) In order to relieve the enormous burdens faced by high impact areas in the course of the HIV/AIDS epidemic, Congress should enact the Comprehensive AIDS Resources Emergency Act of 1990. This bill would provide a major infusion of funds to local health delivery systems so that medical treatment, early intervention, prophylactic therapies and support services can be enhanced or expanded.
- 2) In order to promote appropriate early intervention, Congress should enact the Medicaid AIDS and HIV Amendments of 1990, which would give States the option to expand Medicaid benefits to a broader portion of our underserved HIV infected communities.

- 3) In order to provide critically needed permanent and supported housing as a necessary component of the HIV/AIDS continuum of care, Congress should increase federal funding for housing. We are particularly concerned that the Department of Housing and Urban Development FY 91 Budget does not include specific funds for this purpose. The City supports the AIDS Housing Opportunity Act.
- 4) In order to enable persons with HIV related illnesses to return to or remain in their own homes, Congress should provide full funding for home health care services. The New York City AIDS Task Force estimates that by 1993 the need for home care will be more than 7 times the current capacity to serve indigent clients.
- 5) In order to conduct a major HIV/AIDS prevention initiative among substance using populations, Congress should expand the Alcohol, Drug Abuse and Mental Health Block Grant and AIDS Prevention Programs. A significant Federal increase in the ADAMHA block grant will yield critically needed drug treatment slots.
- 6) In order to attract the types of health providers— nurses, social workers, physicians—integral to the provision of a continuum of care for HIV infected and ill persons, Congress should revitalize the National Health Service Corps, and designate high impact, underserved areas.
- 7) In order to effectively address the particular characteristics of HIV/AIDS as a chronic, often fatal disease with a diminished survival time, Congress should suspend the 24 month waiting period for Medicare eligibility for people with HIV illness or AIDS. Without hastened eligibility for people with AIDS, many will die before the 24 month waiting period concludes.
- 8) To help ease the burden on the small number of hospitals caring for the majority of patients, Medicaid "disproportionate share" requirements should be expanded.

Specifically, states should be required to provide Medicaid rates that fully cover the cost of inpatient and outpatient AIDS/HIV-ill care, thus encouraging all hospitals to serve these patients. The Federal government should also require that state Medicaid plans include provisions for the adequate participation of all hospitals in caring for the HIV-ill or persons with AIDS.

- 9) In order to further support and encourage at-risk populations to avail themselves of early medical intervention, Congress should enact strong legislation to protect HIV-infected individuals from discrimination, and to assure anonymity and confidentiality in the HIV testing process.

[Whereupon at 1:30 p.m., the Task Force adjourned.]



CMS LIBRARY



3 8095 00012578 7